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Care and Support Needs of Children and Young People with Cancer and Leukaemia and Their Families

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Chapter 1 Background

1.1 The study

This report describes a two year project exploring the psychosocial care and support needs of children and young people with cancer and leukaemia and their families funded by the charity, Cancer and Leukaemia in Childhood (CLIC). The key aims of the study were:

- To explore patterns of psychosocial support service provision throughout the UK for children and young people with cancer and leukaemia and their families.
- To describe the needs of children and young people with cancer and leukaemia and their parents over the trajectory of the illness and post treatment.
- To compare patterns of support with parents' and children's/teenagers' views of their needs, and develop recommendations for the voluntary sector's provision of services.

The research was carried out in three stages:

- Stage One – a UK wide postal survey of all NHS paediatric oncology treatment centres (excluding Dublin) and a survey of key voluntary agencies working with these centres.
- Stage Two – a series of focus group and individual face-to-face and telephone interviews with children, teenagers and parents.
- Stage Three – a UK wide postal survey of parents and children/young people.

The methods and results of each stage of the research are reported in separate chapters. A concluding chapter draws together the three research stages in a discussion of the results and highlights key areas of service development. A separate volume of appendices accompanies this report.

1.2 Past research

The need for a "comprehensive strategy for bringing together prevention, screening, diagnosis, treatment and care for cancer" has been recently acknowledged in *The NHS Cancer Plan* (DoH, 2000:5). However, it is important to note that while major advances have been made in the treatment of childhood cancer, with survival rates now exceeding 70 per cent (Cancer Research UK, 2003) evaluation of psychosocial support is less developed.

In the UK, psychosocial support is provided and funded by a number of different organisations. Indeed, support services have developed in a rather ad hoc manner and historically from a time when the pattern of treatment for and survival from

childhood cancer was different. Partly as a result of this, considerable differences exist between different areas in levels and models of support. For example, Hunt (1995) found that paediatric oncology community nurses were funded by the NHS, CLIC, Cancer Relief Macmillan Fund, and other charities. The majority were based at regional treatment centres, with about one third being based within district general hospitals. Major differences in practice were found according to location and funding source. However, past research has tended to focus upon only a few regional centres and little information is generally available about the differing patterns of provision and how these meet families' needs. There is thus a gap in research with regard to documenting and evaluating psychosocial services and the support available to children, young people and their parents throughout the UK.
In light of this, the International Confederation of Childhood Cancer Parent Organisations (ICCCPO) recently produced guidelines on what families should expect in treatment and care (ICCCPO, 2000). These are potentially an important benchmark. The guidelines set out standards in relation to diagnosis and treatment, social and psychological care and reintegration post treatment. The standards cover aspects such as information, economic support, maintaining the child's education, coping support for parents, patients and siblings, and access to support groups.

Past research does recognise the importance and value of providing psychosocial support services. Indeed, there is a substantial body of literature, especially North American based studies, documenting the psychosocial effects of cancer for parents and children/young people and as a result of this, families' support needs (Scott *et al.*, 2003a). This review will initially examine the psychosocial effects of childhood cancer for parents and their subsequent support needs. Recognising that children and young people with cancer may experience different life changes to their parents, this review will also explore the support needs of children and young people. As a result of the complexity of literature surrounding childhood cancer and the scope of this study, the review will not examine in-depth the support needs of other family members (Scott *et al*., 2003b).

1.3 Psychosocial effects of childhood cancer and parents' support needs

Past studies have demonstrated that parents experience a wide range of emotions and experiences when their child has cancer. Childhood cancer is still relatively rare and frequently unexpected; parents may ask themselves 'why?' and look for causality but often to no avail. Hence, uncertainty across the whole disease trajectory is a commonly experienced emotion, from diagnosis and its many unanswered and unanswerable questions, to focusing around the scope, content and success of treatment, to subsequently moving off treatment and the numerous concerns surrounding potential relapses (Eiser *et al*., 1995; Faulkner *et al*., 1995; Van Dongen-Melman, 2000; McGrath, 2001). Distress and uncertainty has, however, also been shown to persist over subsequent years, even when active treatment has ended, the child is in remission and the period known as ‘survivorship’ (usually post five years of treatment ending) reached, there are broader and longer term future concerns (Stuber *et al*, 1994).

More specifically, studies have demonstrated that parents can experience feelings of self-blame, ‘was the cancer triggered by something they did or did not do?’ This has been found to be more prevalent amongst mothers (Eiser *et al*., 1995). Feelings of anger can also occur, particularly a need to blame others, such as medical professionals if they have not acted or diagnosed their child’s illness ‘quickly’ (Arksey and Sloper, 1999; Van Veldhuizen and Last, 1991). In addition, studies have also documented denial, with parents suggesting that their child’s diagnosis cannot be correct (Chaffee, 2001). In light of the many emotions experienced, the importance of preparing and supporting parents throughout the illness trajectory is apparent. Past studies have noted the benefits of professionals discussing future events and treatments before they occur and generally providing parents with time and space to discuss their emotions in a non-judgemental atmosphere, with counselling as an available option (Faulkner *et al*., 1995)

The variability in psychosocial outcomes for parents, for example, how parents approach, react and adapt to their child’s diagnosis of cancer and its subsequent effects on family life has been well documented within theories of stress and coping (Lazarus and Folkman, 1984; Van Veldhuizen and Last, 1991). Within these theories, how parents appraise life events and whether they are perceived as ‘stressful’ depends upon individual assessments and the personal resources (material, physical and social) families have to draw upon. Coping strategies are by no means static but rather change over time and over the illness trajectory, depending on one’s personal assessments and current resources. Indeed, past studies (Kupst *et al*., 1983) have highlighted the danger of professionals viewing coping as a stable phenomenon over time. Different families have and/or prefer different coping strategies and within this, different members of the family adopt diverse coping styles. For example, Mastroyannopoulu *et al*. (1997) found that fathers of children with a non-malignant life-threatening disease adopted more practically based strategies and emotional withdrawal, whereas mothers favoured strategies premised upon emotional release. Such diversity needs to be recognised and as far as possible, taken into account by professionals providing psychosocial support.

1.3.1 Family changes - domestic

It is also apparent that parents face many changes to their everyday lives both on a personal and familial level when their child has cancer. In many ways, there is a need, and an expectation that parents will be able to juggle a number of roles and responsibilities. For example, trying to retain a semblance of normality within the home by continuing tasks such as cleaning, preparing meals and doing the washing for the family as a whole, whilst simultaneously caring for their ill child, and in many cases spending significant amounts of time staying at the hospital with the child and/or attending clinics (McGrath, 2001, Soothill *et al*., 2001; Sloper, 2000; Stein and Woolley, 1990). This issue becomes increasingly pertinent if parents assist with or provide treatment and palliative care in the home for their child (Liben and Goldman, 1998; Goldman, 1996). Pain relief and symptom management can be stressful and time consuming for parents. Other familial responsibilities and roles may suffer, especially in terms of the attention and time parents can give to siblings and their own partners. ‘Normal family life’ is frequently disrupted; many families emphasis the importance of taking ‘one day at a time’, as planning ahead becomes fraught with difficulty and often disappointment (Halliday, 1990). Indeed, Faulkner *et al*. (1995) emphasise the importance of families reassessing and renegotiating what is perceived as ‘normality’.

Recognising the many changes that parents face in their own and their family lives, the provision of practical support, such as help with domestic tasks and childcare, needs to be considered. Indeed, there is an important role for either paid or voluntary workers to help families in their own homes, as this may help ease the dual role parents’ play, trying to juggle domestic normality with caring (McGrath, 2001; Liben and Goldman, 1998; Goldman, 1996). Furthermore, the significance of providing adequate childcare for parents, especially single parents and those distanced from kin networks or without friends/neighbours to draw upon, should not be underestimated. The type of support parents require during the illness trajectory obviously varies, however, as noted above, two key periods when support is invaluable are during treatment and for families providing palliative care in the home.

1.3.2 Family changes - relationships

In light of these changes, it is unsurprising that stressful relationships are a recurring theme throughout the literature. During the illness trajectory, many parents actively seek or are forced to re-assess their relationships with and/or feelings towards family members (Yantzi *et al*, 2001; Van Dongen-Melman, 2000; Sloper, 2000; Halliday, 1990). Indeed, in light of social demographics and family diversification (single parents, stepfamilies), childhood cancer can lead to complex relationship changes or re-affirmations between a child’s biological, custodial or social parents (Gould and Gould, 1994).

In addition, parents frequently react to their child’s cancer in very different ways, although some studies report that this can strengthen spousal relationships, others highlight additional stresses and strains (Chafee, 2001; Mastroyannopoulu *et al*., 1997). On a more practical level, parents often feel that they no longer have, or feel that they have, as much time for one another as before. This is often a physical reality if partners are separated for long periods of time with one parent remaining in hospital and the other in the family home. Parents also report a need to re-assess their own perception of their child with cancer and re-adjust to idea and reality of having an ‘ill’ child (Van Dongen-Melman, 2000; Sloper, 1996). Hence, wider socially acceptable perceptions of what is ‘good’ parenting may be questioned and found to be inappropriate.

Contact with extended family and the role of friends is also an important area of change and psychosocial stress. As noted above, the extent of socially supportive ties is frequently related to levels of stress (Overholser and Fritz, 1990; Kupst *et al*., 1983). Indeed, research has demonstrated the value of ‘having someone to talk to’, not always a partner or member of one’s family, close friends play a key role. However, parents report that they can both gain and lose friends during the illness trajectory (McGrath, 2001; Mastroyannopoulu *et al*., 1997): on one hand, losing contact with friends or family unable to cope with or understand their child’s cancer and on the other, making friends with parents with children similarly facing cancer.

1.3.3 Financial changes

The important financial changes and ensuing practical and emotional problems that families face during the illness trajectory have been frequently noted (Corden *et al*., 2002; Ynatzi *et al*., 2001; Sloper, 2001; Sloper, 1996; Halliday, 1990; Stein and Woolley, 1990). Having a sick child often leads to extra expenditure (for example in areas such as travel, telephone calls, catering for a special diet, fuel) at a time when family incomes are changing. During the illness trajectory many parents, especially mothers, readjust their paid working hours or give up work in order to accommodate caring for their sick child. Financial changes can impact upon families in many ways; from the immediacy of a reduced income, the stress of negotiating state benefits, to career implications for women wishing to return to work at a later date. In light of these many changes and uncertainties, it is unsurprising that parents have been found to want well-timed information/advice about the benefits available to them and the financial implications of potential actions, such as giving up work. One area where this has recently been documented is bereavement (Corden *et al.*, 2002). Here, parents not only wanted information delivered in a sensitive manner by well trained staff but also recognition of the importance of bridging support, i.e. not loosing one’s benefits immediately after the death of a child.

1.3.4 Information

In general, the importance of providing clear, non-jargonistic, accessible information about cancer and leukaemia to parents and other family members cannot be overstated (Jankcovic *et al*., 1999; Sloper, 1996; Eden *et al*., 1994). Research has demonstrated that information giving should not be regarded as a one-off event but rather an ongoing process with regular updates and reviews. Indeed, it has been demonstrated that information is frequently forgotten or not taken in, especially during the early stages of the illness trajectory. Hence, the importance of repetition and delivering information in a variety of formats, such as written and audio-visual to back up conversations (Eden *et al*., 1994). Furthermore, where information is delivered should also be considered, many parents highlight the importance of a quiet and private setting (Stein and Woolley, 1990).

1.4 Sibling support

Although beyond the scope of this study, the psychosocial effects for siblings should not be forgotten. Parents frequently feel that they do not have as much time for their other children, thus leading to feelings of guilt and a recognition that they as parents, often expect more than before from siblings. This can take many forms from providing practical help around the house to emotional support, thus demonstrating greater maturity. Similarly, research has demonstrated that siblings can experience a wide range of emotions from anger and jealousy, to fear and guilt, as they seek to make sense of their changing role in the family and relationship with parents and their 'ill' sibling (Van Dongen-Melman, 2000; Roberts *et al*., 1998; Curnick, 1990). Appropriate support for siblings is thus crucial. As with parents, this should encompass easily accessible, age appropriate and honest information and opportunities for siblings to discuss their feelings and fears (Sloper, 2000).

1.5 Psychosocial effects of cancer for children and their support needs

A child with cancer or leukaemia similarly faces enormous uncertainty throughout the illness trajectory, from diagnosis (what does this mean? will I die?) to treatment (will this hurt? will it be successful?) and in turn, the movement off treatment and facing the future (will the cancer return? what about side effects? how will I face the future?) (Woodgate, 2000; Van Dongen-Melman, 2000; Roberts *et al*., 1998). Many children ask the question 'why me?' and as Bearison (1991) notes, this can lead to many rationalisations, such as the will of God, random chance or a fear that it is punishment for past behaviour. Children with cancer thus experience a potentially broad spectrum of emotions, such as anger, fear, frustration, self-blame, depression and a sense of losing control. Recognising this diversity is pivotal, past research has demonstrated that different children interpret and implement different coping strategies. For example, Kameny and Bearison (2002) found that female cancer patients were more likely to talk about their feelings and emotions associated with their cancer compared to their male counterparts. Indeed, gender and age have been associated with future psychosocial functioning. Bauld *et al*. (1998) found that male survivors had a more negative view of the future than female survivors (see also Sanger *et al*., 1991) and those diagnosed at a younger age generally had a more positive outlook.

1.5.1 Ongoing anxiety

Moving off treatment is frequently perceived as a key milestone, however, it has been demonstrated that this does not automatically lead to reduced anxiety. Returning to hospital as an outpatient can be an extremely stressful experience (Spinetta and Maloney, 1975) and some cancer survivors have reported more negative health concerns and general perceptions of feeling 'different' and social anxiety compared to their non-cancer peers (Bessell, 2001; Lozowski, 1993). Hence, as childhood cancer survival rates continually improve, the importance of 'survivorship' as a separate and ongoing phase, especially for teenagers, gains credence (Eiser *et al*., 2000). In the literature, longer-term issues such as educational qualifications and opportunities, employment and insurance issues, and relationships and future fertility have been noted and are gradually being recognised and studied (Crawshaw *et al*., 2003, Diefer Hicks and Lavender, 2001). Indeed, the value of helping survivors to develop and define their own 'wellness role' has been emphasised (Hollen and Hobbie, 1995). Furthermore, research in the US has also suggested the benefits of establishing separate 'survivor' support programmes, where young people can meet fellow survivors and retain contact with health and social professionals, discussing relevant issues and receiving information (Harvey *et al*., 1999; Hollen and Hobbie, 1995). However, this is an extremely broad and complex area with many sensitive issues and thus requires closer but careful exploration.

In a similar manner, there are numerous studies highlighting the teenage years as potentially problematic and a major area of concern. Although it is recognised that young people generally find the many psychosocial adjustments they face during these years stressful, especially in relation to establishing one's independence, developing relationships, most notably with the opposite sex, and being comfortable with one's physical appearance, cancer is felt to accentuate and add new dimensions to young people's anxieties. Research has highlighted potential tensions as young people struggle to establish and assert their independence but frequently feel thwarted by their dependent cancer status and parents' protectiveness (Roberts *et al*., 1998). Another key area of concern is appearance. Past studies emphasise the negative psychological effects of hair loss, especially amongst females, in terms of self-esteem, body perception and social confidence (Bearison, 1991; Enskar *et al*., 1997; Reid, 1997). However, other studies (Hooker, 1997) have suggested that there is a tendency to over-emphasise the importance of physical appearance, particularly hair loss, amongst teenagers at the expense of other issues. On a more practical note, the importance of age appropriate facilities is also well documented. Attending a teenage unit is frequently valued, from its décor and activities on offer to how staff treat young people (Diefer-Hicks and Lavender, 2001).

1.5.2 Social support - family and friends

Within the literature, the significance of social support during the illness trajectory is apparent, in particular, ongoing family support, especially from mothers, both physically and emotionally during treatment (Ritchie, 2001; Woodgate, 1999, Enskar *et al*., 1997). Hence, the importance of family members, especially mothers, being able to stay with their child whilst they receive hospital treatment. However, this in turn means that other family members (fathers, siblings and grandparents) frequently face long periods of time separated from the child if they remain in the family home (Yantzi *et al*., 2001). Indeed, past research has highlighted a complex emotional picture, as the experience of cancer can both strengthen and weaken family bonds and relationships. Unsurprisingly, it is a very individual experience, interwoven with many other factors, such as past familial relationships, communication patterns and coping strategies (Woodgate, 2000, 1999; Worchel *et al*., 1987). With regard to the latter, children's psychosocial adjustment has been related to parental coping. Those children whose parents adopt more positive coping strategies similarly demonstrated better psychosocial adjustment (Overholser and Fritz, 1991).

The importance of friends, both non-cancer and cancer-related, must also be recognised. Research has indicated that both sets of friends play an important psychosocial role. Cancer friends are often felt to be people who 'really understand' what it means to have cancer, hence, it is easier to discuss one's emotions openly and honestly with them. Non-cancer friends are valued as they help children retain a sense of normality and a link to their non-cancer self (Ritchie, 2001; Woodgate, 2000, 1999; Bearison, 1991). However, due to the protracted nature of cancer and its many physical side effects, socialising with friends, especially non-cancer friends, and doing some leisure activities (particularly physical ones) can be problematic. There is thus a need to provide support for children with cancer, opportunities to meet peers (both cancer and non-cancer) and to engage in a variety of leisure activities. Evaluations of programmes such as activity weekends/holidays for children with cancer (Balen *et al*., 1998; Stirton *et al*., 1997) and teenage cancer support groups (Roberts *et al*., 1998) are generally viewed as positive, providing an opportunity for young people to meet and discuss issues and provide support for one another in a relaxed environment.

1.5.3 Returning to school

During the illness trajectory, many children face long periods of absence from school and their peers, returning to school is thus an important means to re-establish normal routines and continue social, emotional and academic development. It also provides something positive and productive for children to focus upon (Bessell, 2001; Jankovic *et al*., 1999). However, the return to school is often regarded as problematic with children and young people being viewed as more at risk from or exhibiting social and emotional adjustment and behavioural problems, such as depression, social withdrawal and a lack of confidence (Sloper *et al*., 1994; Noll *et al*., 1991). It is interesting to note, that it is often parents, teachers and non-cancer peers who perceive children with cancer as problematic rather than the children with cancer themselves (Arvidson *et al*., 1999). Children with cancer have been shown to view themselves as socially competent (Noll *et al*., 1991) and thus feel frustration when they are treated differently (Bessell, 2001). Returning to school clearly raises many practical and emotional issues for children, from catching up with schoolwork re-establishing social contact with peers, to answering other people's questions about their cancer (Vance and Eiser, 2002; Diefer-Hicks and Lavender, 2001, Larcombe, 1995; Faulkner *et al*., 1995). In light of this complexity, there is clearly a need for well-planned and co-ordinated re-integration programmes between hospitals, schools and family members. Developing such a programme requires careful planning and preparation, in fact, as Larcombe (1995) and Faulkner *et al*. (1995) suggest, preparations should start well before the child re-enters school and involve teachers, health professionals and family members. Within schools, teachers and classmates also need to be prepared and informed of the child's cancer and the possible effects on the child's functioning in the school.

1.6 Overview

The complexity of psychosocial outcomes cannot be overstated. Some young people have retrospectively noted a number of positive cancer related outcomes, such as greater personal maturity, acceptance of others and increased social empathy and altruism (Roberts *et al*., 1998; Bearison, 1991; Smith *et al*., 1991). Similarly, some studies noted that cancer survivors' perceptions of their self-esteem and anxiety levels are comparable to their non-cancer peers (Bessell, 2001; Noll *et al*., 1991; Kellerman *et al*., 1980). Given the diversity and potential enormity of emotions that childhood cancer can lead to and the fact that different children and teenagers experience different emotions at different stages of their illness, the need for sensitivity and understanding amongst professionals seeking to provide support must be recognised. For example, when preparing children and young people for either treatment or the next phase they are entering, it is important to provide them with age and gender appropriate spaces and opportunities to discuss their cancer fears and feelings, and to consider a range of coping strategies. For children, this may involve drawing upon a range of play activities and techniques (Saunders *et al*., 1995; Huddlestone, 1992) and for teenagers, the importance of listening and providing real choices and subsequently respecting and acting upon these, comes to the fore (Diefer-Hicks and Lavender, 2001; Woodgate, 1999; Bearison, 1991). Providing clear and accessible information is once again a key prerequisite within the support equation. How to provide this information is, however, complex, as different children want or need different types and degrees of information at different times. Despite this diversity, the literature has demonstrated that children generally want to be informed of their illness and its severity, in an open and honest manner with regular updates, using age and culturally appropriate language (Diefer-Hicks and Lavender, 2001; Hooker, 1997; Bearison, 1991). Talking in abstract euphemisms and avoiding the word ‘cancer’ has been found to be unhelpful (Bearison, 1991).

Reviewing the broad and diverse literature surrounding childhood cancer, it is clear that providing sensitive and appropriate psychosocial support to children and young people and their families is complex and multi-dimensional, as support needs to be continually reviewed and health and social care professionals need to work together. Psychosocial support needs are interrelated and dynamic rather than static, they are continually changing over the illness trajectory, as families face new situations and challenges, whilst simultaneously coping with everyday life changes, such as their ill child’s changing developmental needs. In addition, service providers also need to be sensitive to the needs of the family unit as a whole, its dynamics, social networks and cultural beliefs and practices, as well as each member’s different needs and ideas. Parents and children/young people’s perceptions of their support needs and coping strategies adopted are not always congruent. In light of this complexity, the importance of a co-ordinator comes to the fore, with each family having a key worker to co-ordinate services and assess/re-assess their support needs. The idea of key workers is by no means new or specific to cancer related illnesses; however, the value of key workers has been advocated for many years but has yet to be widely or uniformly implemented (Greco *et al*., 2004; Valios, 2001; Hynson and Sawyer, 2001; Sloper *et al.*, 1999; Mukherjee *et al*., 1999; Thornes, 1990; Farrell and Sutherland, 1998). Despite this, it is hoped that their role will be further developed, especially in the palliative care field through the work of the Diana nurses (Davies and Harding, 2002; Davies, 1999).

Chapter 2. Surveys of Service Provision

2.1 Survey methods

A review of the literature surrounding the psychosocial effects of cancer and the support needs of parents and children was carried out. From this review, key themes were identified which were presented to the project steering group. Members of the group included representatives from:

- ACT (Association for Children with Life Threatening or Terminal Conditions and their Families)
- Candlelighters
- CLIC (Cancer and Leukaemia in Childhood)
- Macmillan Cancer Relief
- NACCPO (National Alliance of Childhood Cancer Parent Organisations)
- Paediatric Oncology Nurses Forum
- Sargent Cancer Care
- Teenage Cancer Trust
- UKCCSG (United Kingdom Children's Cancer Study Group).

Drawing upon the knowledge and experience of members, topics focusing on the type and nature of support services were identified to investigate through a postal survey of all 21 paediatric oncology treatment centres across the UK (excluding Dublin).

A questionnaire was developed which employed a mixture of closed and open questions to explore the provision of psychosocial and practical support within the treatment centres (see Appendix 1). The questionnaire contained sections on the following areas:

- Centre background information, including information on staff
- Facilities and practical issues
- Psychosocial support services
- Information and advice
- Transition support
- Palliative care
- Staff support
- Additional information.

The questionnaire was agreed with steering group members and piloted with two contrasting treatment centres:

- St James University Hospital, Leeds
- Southampton General Hospital.

Minor amendments were made to the questionnaire and ethical approval obtained from the Northern and Yorkshire Multi-Centre Research Ethics Committee. Questionnaires were subsequently sent to all treatment centres. Within each centre the UKCCSG co-ordinator nominated a member of staff to either complete the questionnaire themselves or to convene a group meeting of relevant staff to complete the questionnaire as a joint exercise. Telephone reminders were made after three weeks and written reminders were sent after ten weeks.

All 21 treatment centres completed the questionnaire. The responses provided data on the overall patterns of support provided in these centres and also on the services provided by four Teenage Cancer Trust (TCT) units based at three of these centres:

- Middlesex Hospital, London (two units)
- Royal Victoria Infirmary, Newcastle
- St James' University Hospital, Leeds.

In order to provide a comprehensive overview of support services available to children and young people across the UK, questionnaires were also sent to the three TCT units not based at the main paediatric oncology treatment centres. These were the units at:

- Christie Hospital, Manchester
- Weston Park Hospital, Sheffield
- Queen Elizabeth Hospital, Birmingham.

However, there was no response from Queen Elizabeth Hospital. Twenty-three centres/units, therefore, responded to the survey.

A database consisting of eight tables to correspond to the eight sections of the questionnaire was created in Access to record the responses from the 23 centres and produce the following report. Some data are missing for individual questions, since not all questionnaires were fully completed.

2.2 Survey results

2.2.1 Centre background information

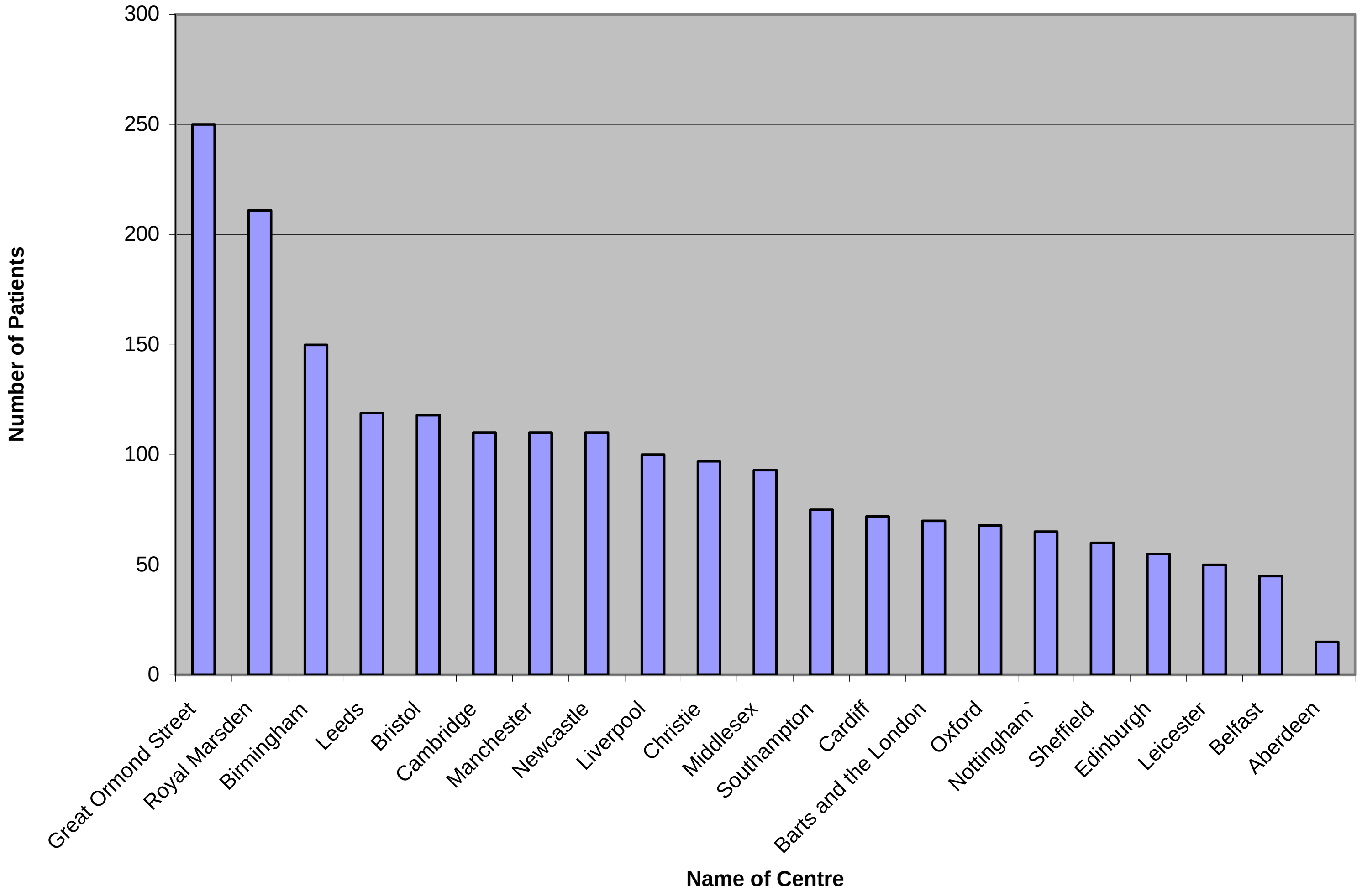
Number of patients

The number of children and teenagers registered with each centre as new patients in an average year varied from 250 to 15, with a mean of just under 100 (97).

Table 2.1 New patients registered in an average year

Name of Centre	*Number of Patients*
Aberdeen	15
Barts and the Royal London	70
Belfast	45
Birmingham	150
Bristol	118
Cambridge	110
Cardiff	72
Christie	97
Edinburgh	55
Glasgow	Missing data
Great Ormond Street	250
Leeds	119
Leicester	50
Liverpool	100
Manchester	110
Middlesex	93
Newcastle	110
Nottingham	65
Oxford	68
Royal Marsden	211
Sheffield	60
Southampton	75
Weston Park	Missing data

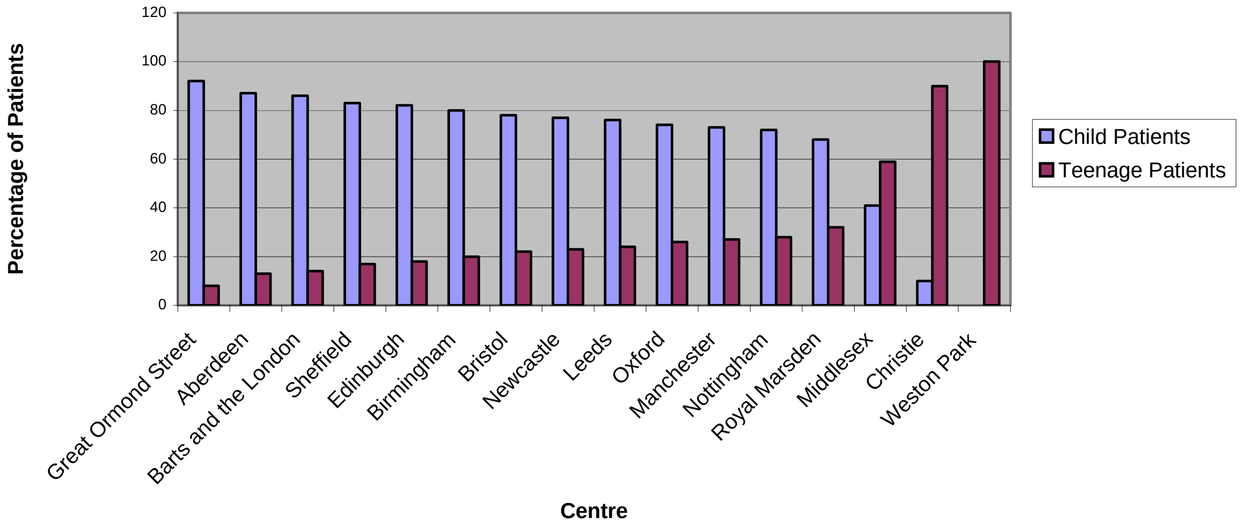
Figure 2.1 New patients registered in an average year



Age of patients

Amongst the 23 centres taking part in the study, 16 provided information on the number of child (aged 12 or under) as opposed to teenage patients. Information was not available from Belfast, Cambridge, Cardiff, Glasgow, Leicester, Liverpool and Southampton. Figure 2.2 shows the proportion of child and teenage patients in each centre.

Figure 2.2 Age of patients



Shared care

Over half the centres (15) reported that they shared care with other hospitals, varying in number from one hospital at one centre to 50 to 60 hospitals at two London-based centres.

Table 2.2 Shared care

Name of Centre	*Number of Shared Care Hospitals*
Great Ormond Street	60
Middlesex	53
Barts and the Royal London	20
Royal Marsden	15
Cambridge	14
Southampton	10
Oxford	9
Bristol	8
Leeds	6
Birmingham	5
Cardiff	2
Glasgow	2
Leicester	2
Nottingham	2
Edinburgh	1

The following centres did not share care with other hospitals: Christie, Liverpool, Manchester, Newcastle and Sheffield. Data on shared care with other hospitals was not available from Aberdeen, Belfast and Weston Park.

Single v multiple sites

Six centres reported that cancer care was delivered on a single site: Aberdeen, Belfast, Cambridge, Christie, Nottingham and Weston Park. The remaining centres used two or more sites to deliver some types of care (see Table 2.3).

Table 2.3 Type of care delivered elsewhere

Type of care	*Name of Centre using a different site to deliver care*
Bone Marrow Transplants	Edinburgh
	Cardiff
	Leicester
	Newcastle
	Middlesex
Care for CNS tumours	Newcastle
MIBG Therapy	Glasgow
Neurosurgery	Bristol
	Leeds
	Leicester
	Liverpool
	Oxford
Orthopaedic Surgery	Bristol
	Cardiff
	Liverpool
	Middlesex
Radiotherapy	Birmingham
	Bristol
	Edinburgh
	Cardiff
	Glasgow
	Great Ormond Street
	Leeds
	Liverpool
	Manchester
	Sheffield
	Southampton
	Oxford
Retinoblastoma	Cardiff
Some specialist cancers	Royal Marsden
Surgery	Birmingham
	Cardiff

Staff

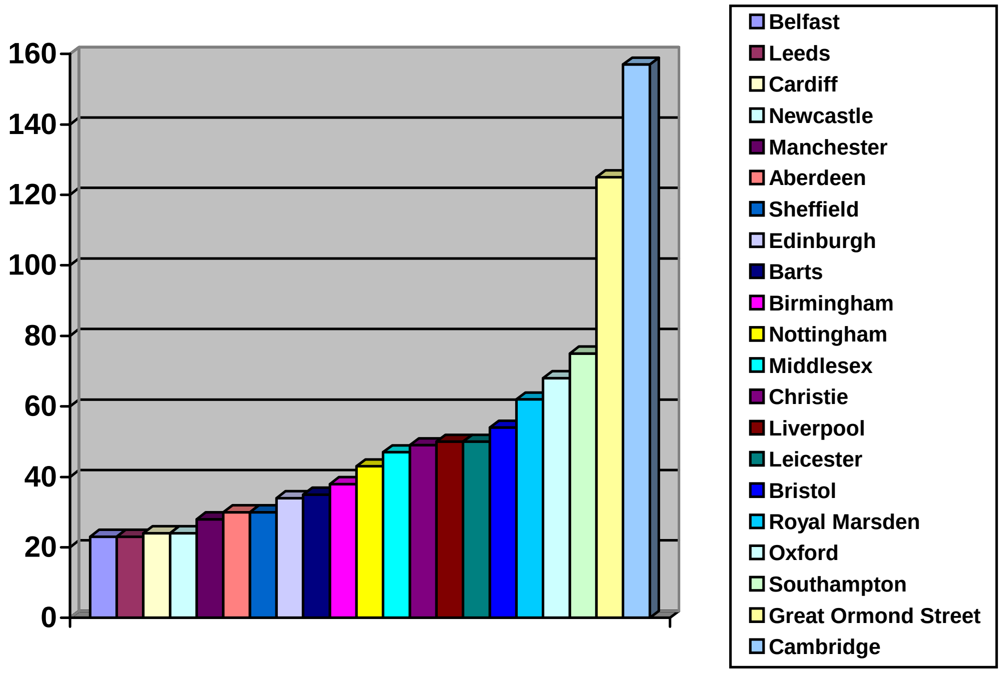
The centres were asked to provide information on staff they employed on a regular basis, rather than staff they had access to if required. Since data on staffing are missing from one centre (Glasgow), the following information is based on 22 centres.

In order to compare the staffing of different centres, ratios of numbers of new patients per year to number of whole time equivalent posts have been calculated. Whilst we acknowledge that social workers and paediatric oncology outreach nurse specialists in shared care units contribute to care, figures reported here are based on staff in the regional centres.

Social workers

Amongst the 22 centres, all but one (Weston Park) employed social workers on a regular basis. However, at the time of the survey one of these 21 centres (Aberdeen) did not have a social worker in post. The number of social workers employed across the centres varied from a minimum of 0.5 in one centre (Aberdeen) to a maximum of 5.2 in another (Leeds), with a mean of 2.3. The ratio of patients to social workers varied from at best 23:1 in two centres (Belfast and Leeds) to 157:1 at one centre (Cambridge), (see Figure 2.3).

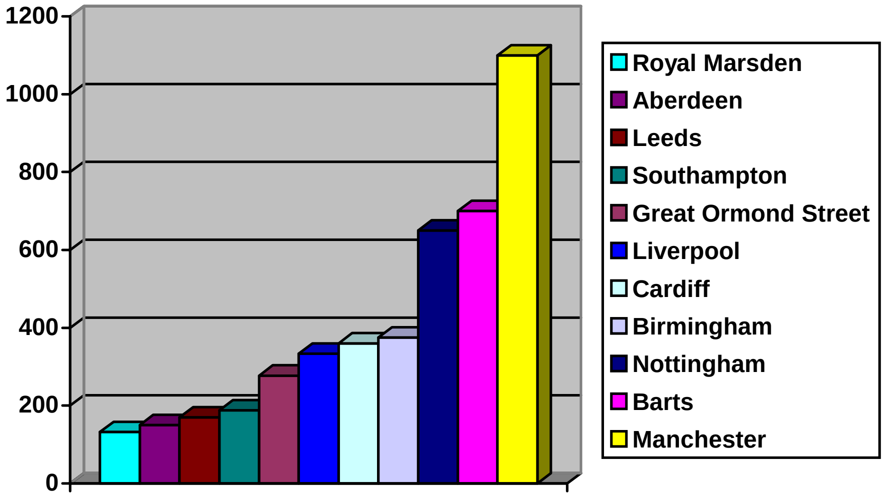
Figure 2.3 Ratio of patients to social workers



Seventeen centres provided data on the source of funding for social worker posts. The majority of posts were funded by the voluntary sector with all 17 employing social workers funded by the voluntary sector. Only two centres (Belfast and Leeds) also employed social workers wholly funded by statutory sources and three (Birmingham, Cardiff and Leeds) had social workers who were funded by a mix of statutory and voluntary sources. However, in 13 centres the social workers employed were solely funded by voluntary sources.

Psychologists
Amongst the 20 centres providing data on psychologists, 11 employed psychologists on a regular basis. This was typically on a part-time basis, with only four centres employing more than a half-time psychologist post, whilst seven employed less than a half-time psychologist post. Nine centres indicated that they did not regularly employ a psychologist at all. However three of these nine centres noted that they had access to a psychologist if required. In the 11 centres that regularly employed psychologists, the ratio of patients to psychologists varied from 132:1 (Royal Marsden) to 1100:1 (Manchester), (see Figure 2.4).

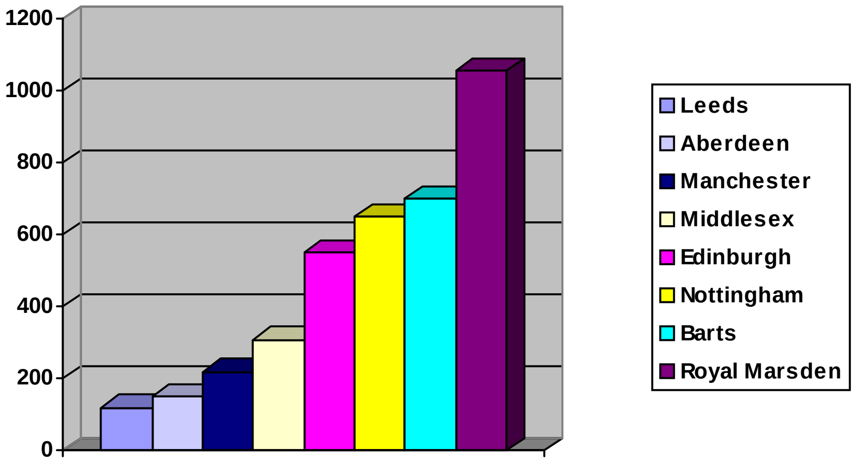
Figure 2.4 Ratio of patients to psychologists



Amongst the 11 centres where psychologists were regularly employed, nine had psychologist posts solely funded by statutory sources. The remaining two funded their psychologist time solely through voluntary sources (Royal Marsden) or through a mix of statutory and voluntary sources (Leeds).

Psychiatrists
Only eight of the 22 centres regularly employed a psychiatrist. This was typically on a part time basis with only one centre (Leeds) employing a psychiatrist on a full time basis. Moreover, four of the centres only had 0.1 whole-time equivalent (wte) psychiatric posts. Where the data were available (for eight centres), the ratio of patients to psychiatrists varied from 119 (Leeds) to 1055:1 (Royal Marsden), (see Figure 2.5).

Figure 2.5 Ratio of patients to psychiatrists



In the seven centres that provided information on funding, psychiatric posts were invariably funded by statutory sources.

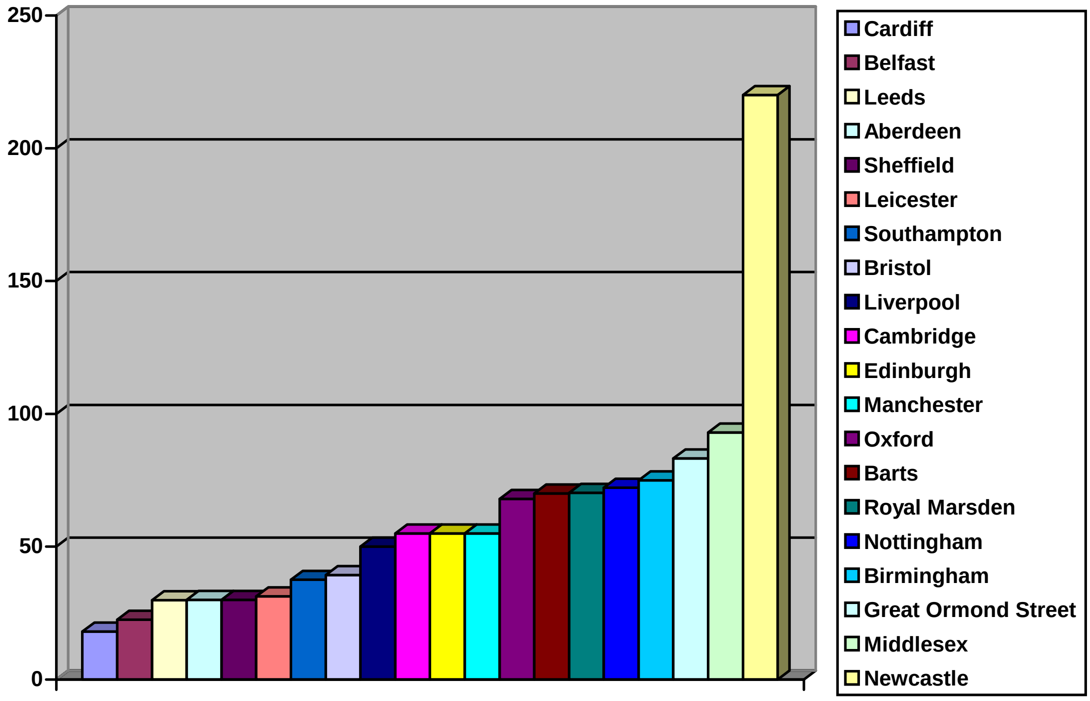
Counsellors

Amongst the 21 centres that provided information on counselling posts, only one centre (Middlesex) employed a counsellor on a regular basis and this was for a 0.8 wte post.

Play specialists

Twenty centres provided data on the number of play specialists employed. All but one (Weston Park) employed a play specialist on a regular basis. The number of play specialists employed in each centre varied from a minimum of 0.5 in two centres (Aberdeen and Newcastle) to a maximum of four in two centres (Cardiff and Leeds), with a mean across all centres of 1.93. The ratio of patients to play specialists varied from 18:1 (Cardiff) to 220:1 (Newcastle) (see Figure 2.6). These figures do not appear to relate to the age of patients across centres. However, the absence of a regular play specialist at one TCT unit where there were no patients under 13 years may be attributable to these teenagers having less need for a play specialist than younger children.

Figure 2.6 Ratio of patients to play specialists

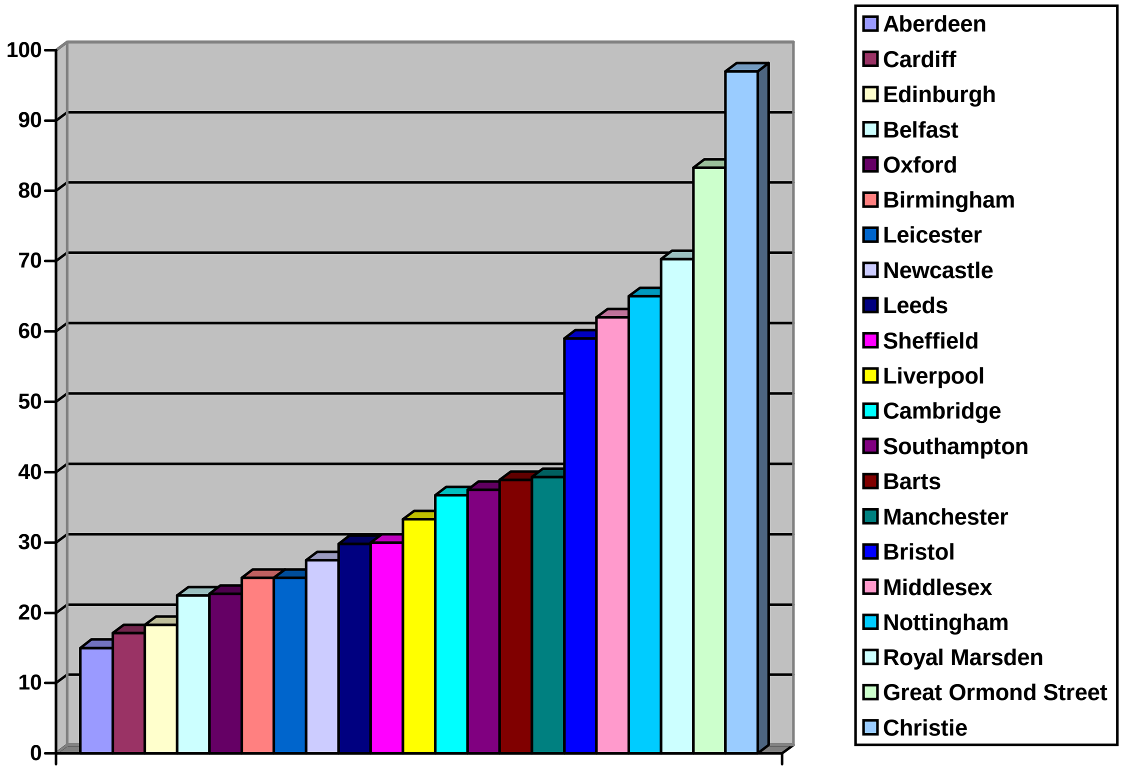


Amongst the 20 centres that regularly employed play specialists, the majority of posts were state-funded. In 11 centres, play specialists were solely funded by statutory sources, whereas they were solely funded by voluntary sources in only two centres (Edinburgh and Newcastle). In seven centres, posts were funded by both statutory and voluntary sources.

Paediatric Oncology Outreach Nurse Specialist (POONS)

All but one centre (Weston Park) regularly employed at least one full-time POONS. The number of POONS posts in each centre varied from a minimum of one in three centres (Aberdeen, Christie and Nottingham) to a maximum of six in one centre (Birmingham), with a mean across all 21 centres of 2.6. The ratio of patients to POONS varied from 15:1(Aberdeen) to 97:1 (Christie) (see Figure 2.7).

Figure 2.7 Ratio of patients to POONS



In the 21 centres that regularly employed POONS, 19 provided information on their funding. In 11 of these centres, POONS posts were solely funded by statutory sources, whereas they were solely funded by voluntary sources in only four centres (Aberdeen, Bristol, Edinburgh and Nottingham). In the remaining four centres, POONS posts were funded by a mix of statutory and voluntary sources (Cambridge, Cardiff, Middlesex and Oxford).

2.3 Facilities and practical issues (Section B)

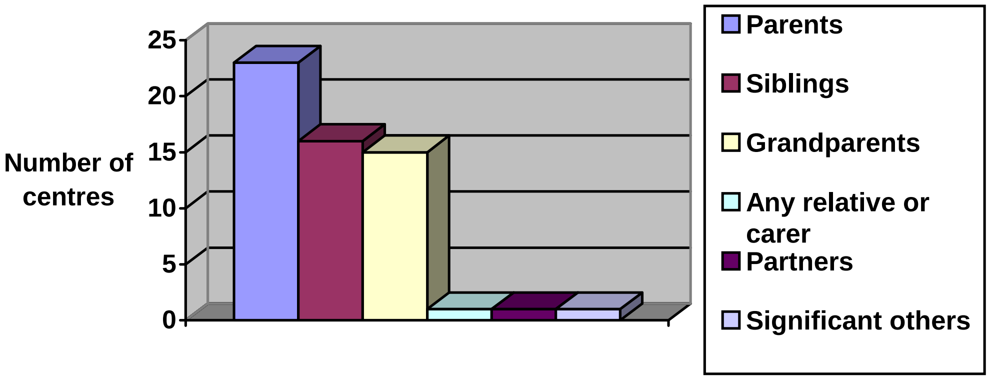
2.3.1 Family accommodation

All 23 centres provided family accommodation. At two centres this was usually restricted to one person per child and at one centre this was only provided for families of patients who were aged under 16 years. However, less than half the centres (nine) provided accommodation for families travelling long distances for an out-patients appointment.

Family accommodation was provided free of charge at most centres (20), but two of these centres required a nominal payment or voluntary contribution for some of their accommodation and one required payment from families staying in local hotels or guesthouses. Only one of the nine centres providing outpatient accommodation charged for this.

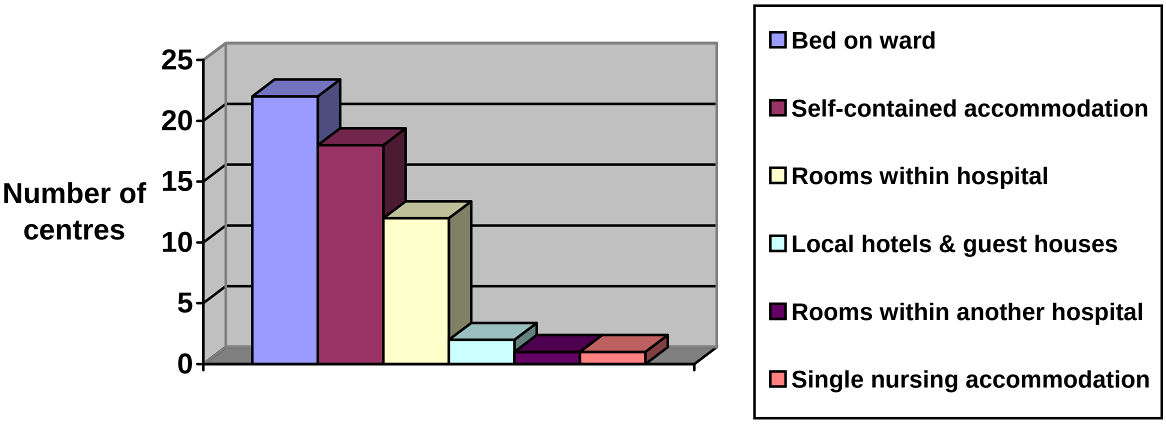
Whereas parents or main carers could be provided with somewhere to stay at all 23 centres, sibling and grandparent accommodation was not always available. Seven centres did not provide any accommodation for siblings and eight did not provide any for grandparents. A further three centres provided limited accommodation for siblings and grandparents. However, three centres provided accommodation for either any relative or carer, partners, or significant others (see Figure 2.8).

Figure 2.8 Who family accommodation is provided for



Family accommodation typically comprised either a bed on the ward (22 centres) or self-contained accommodation (18 centres). Just over a half of the centres (12) provided rooms within the hospital. Other centres provided rooms at another hospital (one centre); single nurses accommodation (one centre) and local hotels or guesthouses (two centres). Most centres (22) provided more than one type of family accommodation and just under a half (10) provided three or more different types of family accommodation (see Figure 2.9).

Figure 2.9 Type of family accommodation



Where family accommodation was provided directly by the hospital (i.e. not in hotels or guest houses), facilities included private washing/toilet facilities and telephones in 22 centres. Family accommodation regularly provided television (21), laundry facilities (20), books and games (19), video/DVD player (19) and self-catering facilities (19). However at one of the three centres not providing laundry facilities in their family accommodation, a washing machine was available in the hospital. Similarly at two of the four centres not providing self-catering facilities in their family accommodation, kitchen/snack making facilities were available on the ward for in-patients. Over half the centres (13) also provided playground facilities for families staying at the centre, whilst one provided a ‘play roof’ that was shared with in-patients.

2.3.2 Patient facilities

At all 22 centres providing data on patient facilities, in-patients invariably received more facilities than day-patients who, in turn, were better served than out-patients. This was the case when examining nine different facilities for patients: bathrooms, kitchen/snack-making facilities, lounge areas, activity rooms for teenagers, computers, playrooms for children, teaching areas/classrooms, televisions and telephones.

All 22 centres provided bathrooms, televisions and telephones for in-patients, but for both day-patients and out-patients, only 13 provided bathrooms and 15 provided televisions and telephones.

Four centres did not provide any kitchen/snack-making facilities for any of their patients. However, these centres typically had fewer teenage patients (generally the most likely to make use of self-catering facilities), with three of the four centres having less than ten teenagers registered with them as new patients in an average year. Moreover, three of the centres without kitchen/snack-making facilities provided self-catering facilities in their family accommodation. Just over half the centres (13) provided kitchen/snack-making facilities for all patients regardless of whether they were a day patient, an in-patient or an out-patient.

The provision of lounge areas for patients and their families was variable with only four centres providing lounge facilities for all patients and their families and three centres providing no lounge facilities whatsoever. Once again, in-patients were the best served, with 13 centres providing a lounge area for their use and 19 centres providing a lounge for their families. Children’s playrooms, on the other hand, were more plentiful, with all centres with child patients providing a playroom for in-patients and only one centre failing to provide this for day-patients and two centres failing to provide this for out-patients. Four centres noted that opening hours of playrooms were limited. Computer facilities were available to in-patients at all centres and to day-patients at 17 centres, but only half provided computer access to out-patients.

There was wide variability in the provision of education facilities to patients at the centres. The majority of centres (20) provided a teaching area or classroom for in-patients. This could be used by day-patients in 14 centres, and by out-patients in eight centres. In most centres (again 20), hospital teachers liaised with each child’s school, but a quarter of these did not have an agreed policy for school liaison. A little over a half (13) held open meetings for school teachers to discuss issues surrounding the needs of their pupils who were receiving or had completed treatment. Policies for the provision of education were agreed in 16 centres, but were only recorded in writing in seven centres. In addition to the 16 centres with agreed policies, two centres noted that they followed statutory guidance in their education provision. One of these two centres also noted that it was currently in the process of drafting a paediatric palliative care policy, which included a standard on education in palliative care.

2.3.3 Family facilities in the centres

When examining family facilities in the centres, the same pattern emerged as with patient facilities: families of in-patients had a wider range of facilities available than families of day-patients, who in turn had more facilities than families of out-patients. Information was not available from one centre on the facilities available in hospital for families.

Amongst the 22 centres that did provide this information, all provided telephones, bathrooms and kitchen/snack-making facilities for families of in-patients, but, for both day-patients and out-patients, 16 provided telephones, 14 provided bathrooms and 11 provided kitchens or facilities for making snacks. The majority of centres (19) provided a lounge area for families of inpatients, but this figure fell to 11 for families of day-patients and seven for families of out-patients. Similarly, most centres (19) provided a washing machine for the use of families of in-patients, but this fell to seven centres for families of day-patients and six for families of out-patients, who are clearly less likely to need laundry facilities on their appointment day.

2.3.4 Hospital transport and parking facilities

Transport for family visits was provided at 18 centres: 11 supplied ambulance or hospital transport; five used transport provided by charities or voluntary drivers; and five hired taxis when necessary. However, transport services were sometimes restricted to patients receiving treatment (three centres); to planned admissions and discharges (two centres); and to one parent and one child (for ambulance transport at one centre). In addition, five centres reported that the centre only provided transport if families had no other means available.

Whilst 19 centres were well served by public transport, only seven centres had parking facilities that were easily accessible. Most centres faced serious parking problems. Two centres did not provide parking facilities at all and relied on expensive NCP car parks nearby, whilst just over half the centres (12) had insufficient spaces available. Of those centres that did provide parking facilities, 16 required payment. However, at one centre, families of long-term patients were usually exempt from parking charges.

2.3.5 Teenage facilities

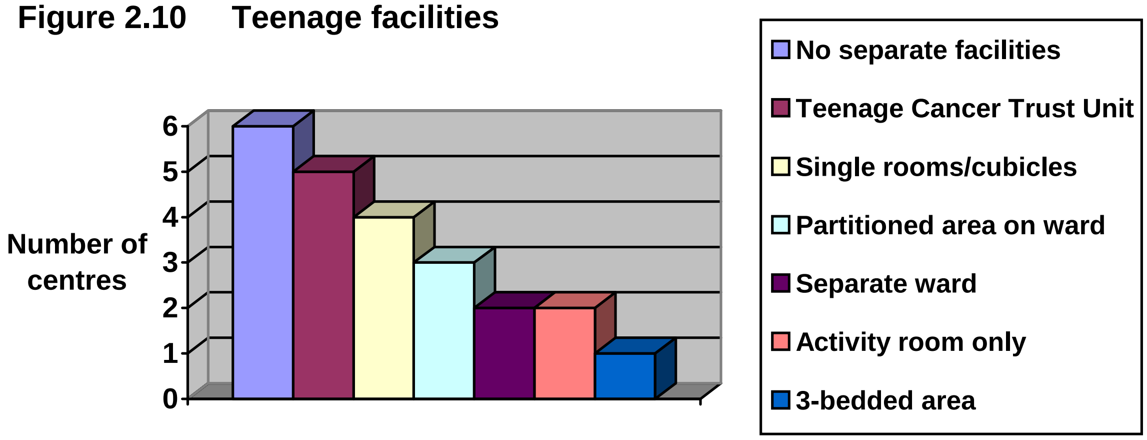
There were separate facilities for teenagers at 17 centres. The provision of teenage facilities in a centre appeared to relate to the number of new teenage patients registered in that centre in an average year. Amongst the 16 centres providing data on the age range of their patients, five centres indicated that less than 20 per cent of their patients were teenagers. Amongst these five centres, three did not provide any separate teenage facilities, one provided an activity room only and one provided a partitioned area on the ward. This suggests that it was those centres with low numbers of teenage patients that had no, or few, separate teenage facilities.

Patients were best served with teenage facilities at the five centres with Teenage Cancer Trust (TCT) units, where young people had their own space with age appropriate décor, facilities and activities. This included one centre that used one TCT unit for day-patients and another for in-patients. A further two centres provided a separate ward for teenagers, although, for staffing reasons, one of these was for non-chemotherapy patients only. Eight centres provided a separate area on the ward for teenagers, with four centres providing some single cubicles or rooms, three centres providing a partitioned area and one centre providing a three-bedded area. Six of these eight centres also provided a lounge and/or an activity room for teenagers.

In contrast, two centres only provided an activity room for teenagers with no other separate facilities. One of these centres however, only had two new teenage patients registered in an average year. Six centres did not provide any separate facilities at all. Where the data were available (for four of these six centres) the proportion of teenage patients at these centres varied from 28 per cent to eight per cent, with between 10 and 20 patients in each of the four centres.

Figure 2.10 shows the number and type of separate teenage facilities available across the centres.

Figure 2.10 Teenage facilities



2.4 Psychosocial support services (Section C)

2.4.1 Assessments and supportive preparations

Formal psychosocial assessments of patients were not routinely made. Indeed, only three centres reported formally assessing every child patient. Most centres (20) carried out an informal assessment of all new patients and only followed this with a formal assessment if a need was identified, such as behavioural problems, or for specific treatments, such as cranial irradiation. Families of all patients received some form of assessment in sixteen centres. Five centres only performed an assessment if a particular need was identified and one centre did not carry out family assessments.

The most frequent method of assessment was an individual approach from a social worker, psychologist or nurse (13 centres), however, ten centres adopted a team approach. Social workers were involved in psychosocial assessments either exclusively or as part of a team in the majority of centres (18). Psychologists only routinely performed assessments in three centres and a psychotherapist in one centre (a TCTU). Whereas social workers met all patients and all families in most centres (20), psychologists did not meet all patients or all families in any centres.

Assessments were usually carried out soon after diagnosis (20 centres for patients and 19 for families) and information was typically recorded in multi-disciplinary team or professional case notes, in case files or a combination of both. Two centres used the Framework for the Assessment of Children in Need. Seven centres reported carrying out regular assessment reviews, but the frequency of these reviews varied from on each admission to every three to six months. Most often, assessments were reviewed on an informal basis as required (ten centres) or as an ongoing process (four centres). However, in one centre reviews were carried out rarely, if at all, and from another, data were not available.

All centres, except one, held regular meetings for staff to discuss the needs of patients and their families. These meetings were attended by multi-disciplinary teams, which sometimes included a psychologist or psychiatrist and teacher, but regularly included medical and nursing staff, social workers and play specialists.

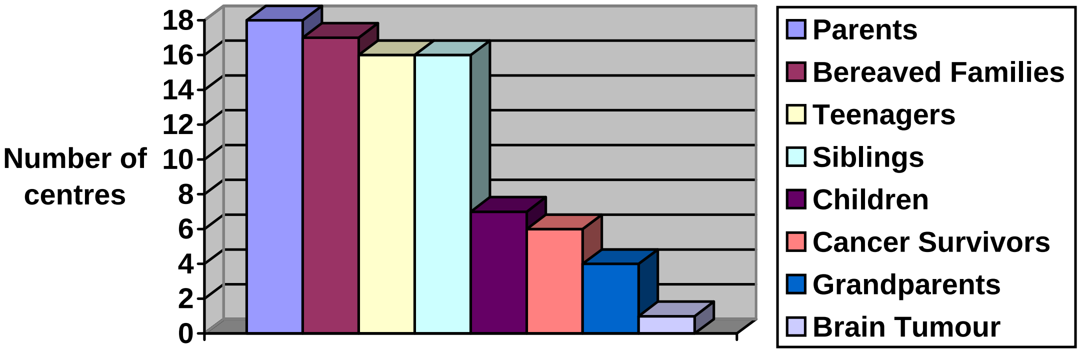
When it comes to the psychological preparation of children and parents for invasive treatment procedures, such as scans, radiotherapy and central line insertions, play specialists were regularly involved. Using a variety of distraction techniques and play activities such as role-play and modelling, books and photographs, and specialist play aids, including dolls and mock scanners or radiotherapy machines, they prepared children for painful treatments. Psychologists, on the other hand, were only occasionally involved, with only four centres reporting input from psychologists in the preparation of patients and families for specific treatment procedures. In two of these centres, bone marrow transplant patients were always referred to a psychologist before receiving treatment and in one further centre (a TCT unit) a child/adolescent psychotherapist was also involved in preparations.

2.4.2 Support groups

Support groups could be accessed from 21 of the 23 centres. However, this was limited to only two or three different types of support groups at nine centres. Three centres, on the other hand, provided six different types of support groups, and two centres provided seven or eight different types.

Support groups for parents and bereaved families were the most common, with these available at 18 and 17 centres respectively. Groups for patients themselves were also accessible, but these were more typically groups for teenagers (16 centres) than for children (seven centres). This is despite the fact that the majority of centres report having more child than teenage patients. Other available support groups included groups for siblings at 16 centres, for grandparents at four centres, cancer survivors at six centres and for brain tumour support at one centre.

Figure 2.11 Support groups



However, support group meetings were not always regularly held or well attended. For example, seven of the 16 reported sibling groups only met sporadically (every few months at three centres, once or twice a year at three centres and ad hoc in the holidays at one centre), one was specifically for siblings of bone marrow transplant patients, and only three families attended one of the centre's groups when it last met.

The majority of support groups were organised by the centres themselves, but at eight centres some of the groups were run by local voluntary organisations, such as Tak Tent for cancer survivors, the Forget-me-not Trust for bereaved parents, SPOCC for parents of children with cancer, Siblinks for siblings, and CHICS for the children themselves.

2.4.3 Bereavement support

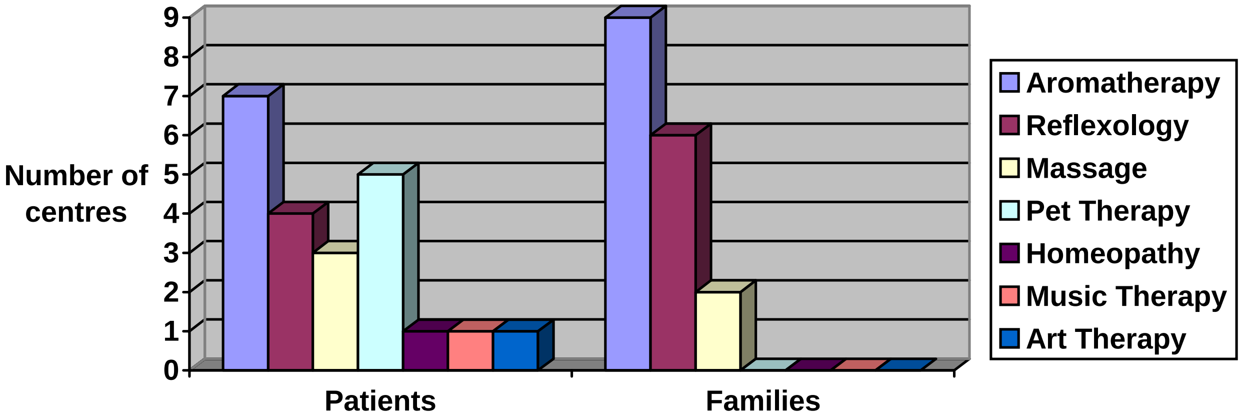
In addition to the support groups for bereaved families noted above (17 centres), social workers (16 centres) and nursing staff (15 centres) regularly provided bereavement support.

However, the type of bereavement support available varied considerably amongst centres. Support from social workers and nursing staff included home visits in at least eight centres, with four centres reporting support specifically provided for siblings. Consultants were involved in providing follow-up or ongoing support to bereaved families in four centres and two centres reported support provided from hospital chaplains or psychologists. Over half the centres (14) referred bereaved families to local bereavement centres and to other external bereavement agencies, such as Cruse Bereavement Care and the Child Death Helpline. In addition, one centre provided a 'befriending service' where bereaved families were put in touch with a trained befriender who was also bereaved.

2.4.4 Complementary therapies

Just over half the centres (12) offered patients some form of complementary therapy and ten centres offered this as therapeutic support to their families. Six centres provided more than one type of complementary therapy but none provided more than three. The most common treatments for both patients and families were aromatherapy and reflexology. Families had greater access to these therapies than patients, with nine centres providing aromatherapy to families and seven to patients, and six providing reflexology to families as opposed to four for patients. In addition, three centres offered remedial massage to patients and two to their families. Pet therapy for patients was provided at five centres, whilst homeopathy, music and art therapy were each offered at one centre. Two centres referred patients and families outside the hospital for alternative therapies and another could refer patients elsewhere within the hospital for therapeutic massage, aromatherapy and acupuncture.

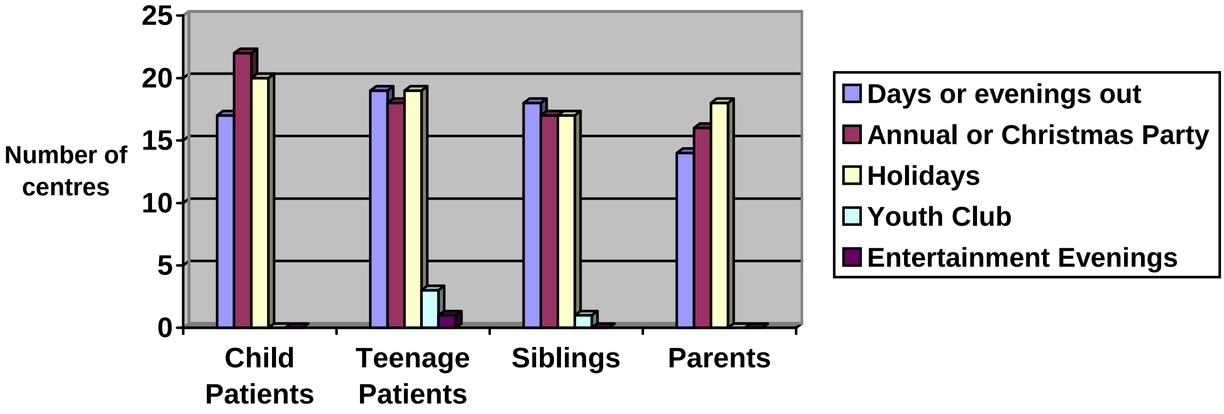
Figure 2.12 Complementary therapies



2.4.5 Informal support

All 23 centres provided informal support to child and teenage patients and their families through organised leisure activities. Slightly more activities were provided for child than teenage patients, but putting this in context, there were considerably more child than teenage patients across the centres. Activities regularly included days or evenings out, an annual or Christmas party and holidays for children and teenagers receiving treatment and for their siblings and parents. Occasionally these included a youth club. One of the teenage centres reported providing entertainment evenings on the unit, such as pizza or video nights.

Figure 2.13 Informal leisure activities



2.4.6 Cultural needs

Providing services and information in an accessible manner is particularly important for families from ethnic minorities, especially those whose first language is not English. The survey showed that 17 centres reported taking the cultural needs of different families into account. This was primarily achieved through the provision of translating and/or interpreting services; with these available in 15 and 13 centres respectively. In five of these centres, the importance and value of translated children's booklets provided by Sargent Cancer Care was noted. Other, more general measures reported included celebrating different cultural festivals (two centres) and providing prayer rooms for different faiths (two centres); recruiting specialist staff, such as first language support workers (four centres) and raising awareness amongst staff of different cultural needs (two centres); and catering for special diets (three centres). Six centres reported that nothing had been done to make the psychosocial support they provided culturally responsive. These were largely centres that did not have large ethnic minority populations. However, there were one or two exceptions. Three centres with large urban and culturally diverse populations, which did provide accessible information for ethnic minority families, did not feel that the psychosocial support they generally provided was responsive to the cultural needs of minority families.

2.5 Information (Section D)

2.5.1 Cancer and leukaemia information

Just over half (13) of the centres had agreed policies for the provision of information about cancer and leukaemia to parents/carers, however, only 11 had agreed information policies specifically for children and teenagers. Very few centres (five) had their information policies formally recorded in writing.

Figure 2.14 Types of information routinely made available to families

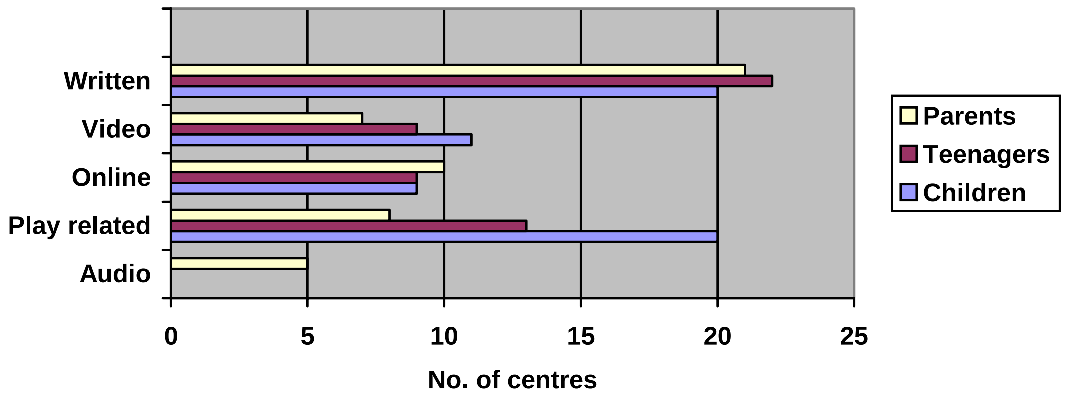


Figure 2.14 clearly indicates that written information, i.e. the traditional form of provision, was most frequently provided by centres. Twenty-two centres provided written information for parents and teenagers and 20 centres for children. The second type of information most routinely provided was play related information for children (20 centres) and teenagers (13 centres). Access to online information resources was available at just under half of the centres. It appears that if a centre provided online resources, then this service was usually available for children, teenagers and parents. Centres also routinely provided information via video more frequently for children (11 centres) than for teenagers (nine centres) or parents (seven centres). On the other hand, audio information was not available for either children or teenagers at any of the 23 centres, and was only provided for parents by five centres.

2.5.2 Family involvement

Just over half (14) of the centres indicated that service users and their families had been involved in the production of, or were consulted when reviewing, information. More specifically, 12 centres indicated that either parents or teenagers had been involved but only six centres had worked with children. However, it is important to remember that not all 23 centres worked with children, a small number focused upon the teenage years.

Some of the ways that family members had been involved appear to be innovative or ongoing rather than one-off events. For example, at four centres parent representatives sat on information review panels or were regularly asked to comment on information. At two centres, teenagers had been actively involved in the development of information videos, one addressing the important issue of returning to school. Finally, the play specialist at one centre had worked with children to develop a preparation booklet explaining a range of treatments (Hickman lines, N/G tubes and PEG feeding tubes) and addressing wider issues, such as hair loss.

2.5.3 General information

Most centres (18) provided families with a hospital or ward welcome pack comprising a range of general information and advice. However, only five centres provided a separate information pack for children and teenagers.

2.5.4 Financial information

Twenty-two of the 23 centres had a designated person providing financial information and advice. At one centre this post existed but was currently vacant. Furthermore, at all 23 centres families were given help in completing application forms, such as Disability Living Allowance, and at 20 of the centres, financial information was routinely provided to all families. Social workers were the main providers of this information and advice at all 23 centres. More specifically, at ten centres it was Sargent social workers.

When asked about policies for complaints and service user feedback, just under three-quarters (16) of the centres felt that they had a process within which families could routinely feedback their comments and feelings to service providers. The examples centres gave were a mixture of formal procedures, for example, complaints forms and satisfaction surveys, and informal routes, such as comment boxes on wards and talking to staff. Even when formal complaints procedures were in place, the ways in which families discovered them were variable. In 15 centres families could find out about complaints procedures via posters, leaflets and PALS notices around the hospital.

2.6 Transition support (Section E)

2.6.1 Hospital to home: outreach service

Twenty-two of the 23 centres indicated that they provided an outreach service for families within their local community. The one centre that did not provide a hospital to home outreach service was a recently established teenage unit. In the 22 centres, nursing staff were the main providers, in fact, in every centre POONS were involved in outreach support. However, other professionals were also involved, as listed in Table 2.4.

Table 2.4 Main providers of outreach support

Type of professional	*Number of centres*
Paediatric oncology nurses	22
Community based nurses	9
Social workers	8
Psychology service	2
Play specialists	1
Therapists (physiotherapists, occupational)	1
Home tuition service	1

As Table 2.4 demonstrates, POONS were the main providers of outreach support, with generic community based nurses also providing support in nine centres. Social workers were the second professional group with a key role in providing support (eight centres). The use of other professional groups, such as home tutors, psychologists, play specialists and therapists, as outreach support providers was infrequent. In half of the centres (11) outreach was distributed amongst two professionals, often POONS and social workers. In four centres, three or more different types of professional provided outreach support and care. Having a larger, more diverse team did not appear to be related to centre size, as these four centres varied in size and the number of patients they served.

The majority of centres routinely provided three types of outreach support: home visits, telephone advice from a doctor or nurse and continuing social worker support. All 22 centres providing a service noted that they undertook home visits and that continuing social worker support was available for both patients and family members. All 22 centres offered telephone advice for family members, but only 19 centres provided this for patients. It is unclear why these three centres did not provide telephone advice for patients. It does not appear to be age related, as the three centres did not specially focus on children within the younger age range, such as the under fives. Continuing support from a psychologist was available at just over half (13) of the centres for patients and 11 centres for family members. Data on other forms of outreach support, such as the provision of respite care and counselling were vague and incomplete. This was partly due to problems of definition and interpretation amongst the different centres.

All 22 centres providing data reported that their outreach workers met with community-based professionals and also arranged joint visits. More specifically, when asked which professionals they met and liaised with, a range of health, social and educational workers were noted, as Table 2.5 demonstrates.

Table 2.5 Community based professionals with whom centres liaise*

Type of professional	*Number of centres*
GP	18
Health visitor	17
District/community nurse	12
School/nursery staff	10
Social worker	8
Therapist (physiotherapist, occupational)	3

*One centre did not complete this section and three other centres did not specify the community-based professionals they liaise with, noting that it depended on each individual.

Amongst the 18 centres that completed this section, GPs and health visitors were the two professionals that outreach workers most frequently met with. Over half of the centres reported that outreach workers also met with district/community nurses (12) and school/nursery based staff (ten) but only eight centres met with community-based social workers. Meeting with community-based therapists was also limited (three centres).

2.6.2 Hospital to home: handover procedures

The survey indicated that three-quarters of the centres (18) had procedures laid down for the transition of care from hospital to home. Amongst these 18 centres, 14 applied procedures to all discharges, whereas four centres were more selective in their application. For example, in two centres, procedures were only applied to new patients and in another two, they were only applicable when there was an identified need or in special circumstances. Amongst the five centres that did not have procedures laid down, there did not appear to be any common factors, such as size or involvement in shared care with other hospitals.

Amongst the 18 centres with procedures laid down, over half (11) had a designated person responsible for handover from hospital to home. This was usually a nurse, specifically POONS in five centres. In three centres, the identified person was voluntary sector funded, either a CLIC or Macmillan cancer specialist. Other staff, although not designated as the responsible person in their centre were noted as involved in handover procedures. Once again, nursing staff, whether community nurses (seven centres), POONS (three centres) or centre based (four centres) were often highlighted, alongside social workers (nine centres). In contrast, professionals such as GPs (four centres) and therapists (physiotherapists and occupational) (two centres) were less frequently involved. However, the data were partial, as seven centres did not specify the staff involved using such terms as ‘all on the ward round’, the multi-disciplinary team or the primary care health team. This diversity appeared to be linked to an informal/formal split, as some centres had formal procedures and designated staff, whereas others had more informal practices with staff involvement depending on each individual case.

Family involvement is also an important element of hospital to home transitions, not only for parents and carers but also for children and young people. Twenty-two centres reported regularly involving family members in the handover decision-making process. One centre did not provide any data.

Table 2.6 Family member involvement by centre*

Family member	*Number of centres*
Child/teenager	21
Parents	22
Siblings	6

* Based on data from 22 centres

Table 2.6 demonstrates that all the centres reported that they regularly involved parents and only one centre did not regularly involve children/teenagers in handover decision-making. However, this centre subsequently contradicted this in a more open-ended question later in the survey. Siblings were not routinely involved within centres (six). When asked about any other family members, only one centre noted the regular involvement of grandparents.

More specifically, when asked ‘has anything been done to involve children and teenagers in the decision making of their handover?’, 16 centres reported taking action. Eleven centres had taken steps to involve children and 14 centres to involve teenagers, (one centre that did not involve teenagers, worked specifically with younger age children). The survey also demonstrated that children and teenagers were involved in the decision making of their handover via informal discussions rather than formal procedures and practices, as these comments illustrate:

> ‘they are asked informally about what they want’
>
> ‘verbal liaison prior to discharge’
>
> ‘discussion one to one and group’

Most centres (21) reported that they had taken steps to involve parents in handover procedures. Once again, this was usually via informal processes, such as chats with staff. Only four centres indicated that they had formal procedures, such as a written checklist, agreement or letter that parents contributed to or comment upon. Only ten centres had family involvement procedures formally recorded in writing.

2.6.3 Returning to school

The survey showed that most of the centres (20) had a designated person responsible for assisting the transition of children and teenagers returning to school. Two of the three centres without a designated person specialised in the teenage years, a time when school and course work is of pivotal importance. However, one of these was recently established. In seven centres, there was more than one designated person. Nursing staff, particularly POONS, were the most frequently noted professionals (14 centres). Teachers were the second most frequently noted professionals in just over half of the centres (12). Although not regarded as designated persons, three-quarters (16) of the centres indicated that other staff were involved in return to school preparations. Social workers were noted in 12 of these 16 centres and once again, nursing staff (ten centres) and teachers (nine centres) were involved in transition preparations.

Families were regularly involved in return to school preparations in 21 of the 22 centres. The one centre that did not indicate regular family involvement noted that involvement occurred in special circumstances, such as assessing a physical disability. This centre did not have a designated person responsible for the transition back to school. Children, teenagers and parents were regularly involved in 21 centres. For children and teenagers, involvement was most frequently noted as inclusion in transition discussions with professionals (13 centres), for example, in relation to returning to school anxieties, information given to schools and individual needs. For parents, involvement, once again, focused upon transition discussions with educational and medical professionals (16 centres). Parents attending school visits was also noted by seven of these centres. Just over half (12) of the centres involved siblings in return to school preparations. In two of these centres, a professional might visit the sibling's school in order to talk to their teacher or the class.

The survey asked the centres 'where does liaison usually take place?' The school was the most frequently noted venue by 21 of the 22 centres. Liaison also took place in the home (15 centres) and the treatment centre (14 centres). Indeed, in half of the centres (11) liaison usually occurred in all three places.

During the transition process, over half (13) of the centres routinely provided information for school and teachers in the form of booklets or leaflets, especially the 'Welcome Back' booklet published by Cancer Research UK. Furthermore, half of the centres also indicated that they routinely provided information regarding a child's illness, such as diagnosis, treatment or care needs. Although many of the centres had a designated person responsible for transition, regularly involved family members and provided information to schools, only ten centres had the procedures to be followed during school liaison formally recorded in writing.

2.6.4 Transition to adult services

There was considerable variability in when young people were transferred to adult services. For those still receiving treatment, nine centres did not transfer care to adult services, age of transfer at other centres ranged from 14 to 21 and two did not have any set ages. For young people who had completed treatment, 11 centres did not transfer follow-up care, age of transfer at other centres ranged from 14 to 23, and two did not have any set ages. Three centres noted that they would hand over care to adult services if the young person relapsed or developed other illnesses. However the age at which this would occur varied from 16 to 20. None of the centres had formally agreed procedures or policies recorded in writing.

In addition, one TCTU described transition to adult services as ‘a very grey area’ due to the ‘extended age range of patients, recently up to 24 years’. In practice, beyond 24 years this TCTU provided ongoing support for patients via their paediatric consultant even if the young person was located on an adult ward.

The survey showed that seven centres had actively taken steps to involve young people in planning their hand-over to adult services. These were predominately informal processes and procedures, such as discussions with young people about their wishes and feelings. Six of these seven centres sought to involve parents in the transition process, once again, with informal discussions and consultations. The number of centres involving family members in hand-over procedures may appear to be small, however, this must be seen in context. As noted above, a number of centres did not hand over care and many centres did not have agreed hand-over procedures. Indeed, none of the 23 centres had formally agreed policies or policies recorded in writing for the transition from child to adult services.

2.6.5 Long-term survivorship

When asked: ‘Do you provide ongoing psychosocial support for long-term survivors of childhood cancer or leukaemia?’, the survey received a varied response. Just under half of the centres (11) indicated that they provided ongoing psychosocial support for long-term survivors. This included centres of varying sizes; those providing shared care and also centres serving both children and teenagers. Amongst the remaining 12 centres, three noted that they provided some support, however, it was not regarded as ‘ongoing’ but rather problem focused, dealing with individual problems, as and when they occurred.

Amongst the 11 centres providing ongoing support, seven had a designated person(s) providing support. Consultant oncologists were the most frequently stated source of support (five centres) with nurses, social workers and psychologists each noted at two different centres. However, only one of these seven centres used the specialist terms ‘long-term follow up consultant’ and ‘long-term follow up sister’ to describe these staff and their role. In addition, six of the 11 centres also indicated that a range of other staff were involved in long-term psychosocial support, once again, these included social workers, consultants, nurses and psychologists. The support actually provided to long-term survivors was variable. The data did not highlight any clear pattern or procedures: provision ranged from ‘open door’ policies, providing support ‘as required’ by individual patients, to centres providing an annual check-up or a specific number of late effects clinics per year. The number of clinics held similarly varied amongst the centres from four per year to twice monthly. This general lack of uniformity was reiterated by the fact that only three of the 11 centres stated that they had formally recorded in writing their policies for long-term survivorship psychosocial support.

2.7 Palliative care (Section F)

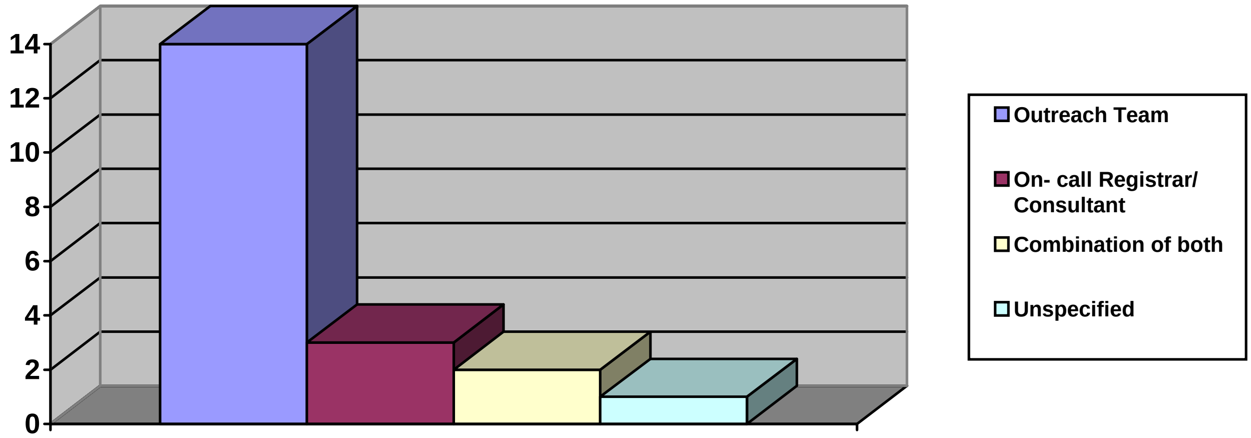
The survey indicated that the choices available to patients and their families requiring palliative care focused upon where they would like care to take place. At all 23 centres patients and their families were offered the option of or a combination of care in the home, hospital and hospice.

Although all the centres felt that families attending their centre had access to a children’s hospice, the survey showed that access was far from uniform. Indeed, the type and degree of questionnaire information provided by centres about the hospices they accessed varied. For example, nine centres provided only the name of their hospice or they merely noted that a hospice was available depending on a family’s wishes. Five centres noted the importance of access via professional referrals. In particular, referrals from consultants, nurses or social workers. In contrast, four centres highlighted that accessing hospices could be difficult for families due to problems of distance and availability. For example, two centres stressed the long distances that their families had to travel to use children’s hospices. In consequence, one centre noted that the hospice was ‘rarely used’, as it was over a 100 mile trip. In addition, two other centres focused upon problems of restricted access, with one hospice only open weekdays and so unable to provide weekend support and another centre noting that families had only been able to utilise day care to date.
In response to the question: ‘how does your centre work with children’s hospices?’, the survey received a varied response. Four centres did not provide any information; six centres suggested there was little contact with hospices, highlighting reasons ranging from poor working relationships to families preferring to use alternatives to hospice care. Nine centres noted general liaison and referrals and only four centres indicated that centre staff worked closely with hospice staff, particularly in terms of providing education and training to hospices.

Similarly, when asked about services provided to families receiving palliative care at home, centres once again provided information which varied in depth. However, the data did indicate that outreach nursing staff, typically POONS, played an important role caring for the patient and their family and also liaising with and co-ordinating other service providers, such as primary care teams and social workers.

The provision of a 24-hour on-call service for families receiving palliative care was available at most of the centres (21). This was largely the responsibility of an outreach team with expertise in palliative care. In 14 centres this service was exclusively provided by an outreach team; in four centres exclusively by an on-call registrar or consultant; and in two centres by a combination of the two. Nursing staff provided this service in one centre. Amongst the two centres that did not provide a 24-hour on-call service, it must be noted that one centre was extremely small both in terms of new patients admitted each year and staffing levels.

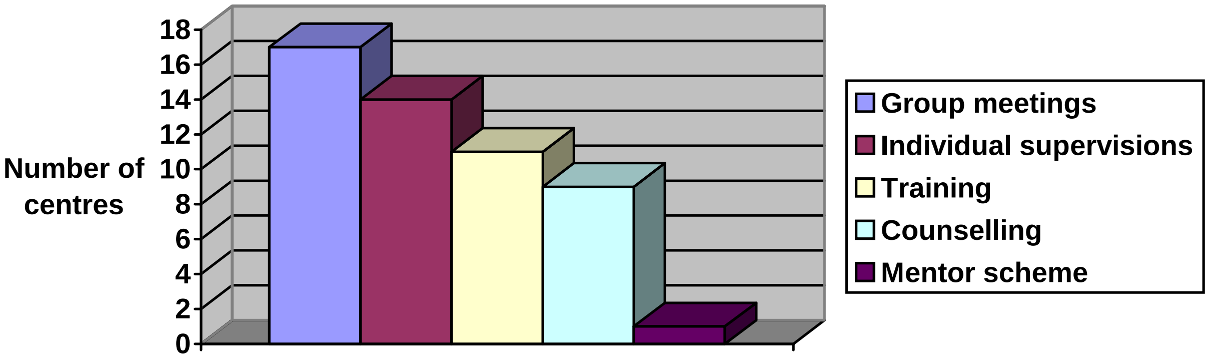
Figure 2.15 Who provides 24-hour on call service?



2.8 Staff support (Section G)

Eighteen centres provided regular psychosocial support for staff through group meetings (17 centres), individual supervisions (14 centres), training (11 centres), counselling (8 centres) and a mentor scheme (one centre).

Figure 2.16 Types of staff support



However, on closer examination there was considerable variation in the frequency and nature of the psychosocial support provided. Group meetings, for example, were held weekly or monthly in seven centres, but on an ad hoc basis as required in five centres. In some centres these meetings were facilitated by a designated person such as a senior nurse, social worker, chaplain, psychologist or psychiatrist (eight centres), whilst in others, meetings were less structured, with group members offering mutual support (two centres). Staff counselling was reported to be available at nine centres, but only two centres referred to the availability of a formal counselling service.

There was also considerable variation in support provided for different types of staff, with some centres noting more frequent supervisions for certain categories of staff, such as social workers, outreach nurses, BMTU staff and play specialists, than for others. Indeed, one centre noted that whilst there was staff support in the form of group meetings and individual supervisions for some workers, there was no formal psychosocial support for staff generally. Moreover, five centres did not report providing any regular psychosocial support for their staff.

Ten of the centres providing staff with regular psychosocial support report that it was well used. Centres explained this by noting the stressful nature of the work and the consequent need to reflect and discuss concerns (three centres), and by working in a close, cohesive team (one centre). Five centres, on the other hand, reported a low take up of staff support provision and attributed this to the formality of structured support sessions (two centres), as well as to shift patterns and work load pressure (one centre), and to confidentiality issues in a small hospital (one centre). At three centres, the take up of provision was variable depending on individual cases, although one of these centres noted that it was well used by certain staff, such as POONS.

2.9 Additional information (Section H)

The survey concluded with a series of open questions exploring voluntary organisations, service gaps and areas of duplication between the statutory and voluntary sector.

2.9.1 Voluntary organisations

When asked ‘which voluntary organisations does your centre work with in the provision of psychosocial support?’, the most frequently reported organisations were Sargent Cancer Care for Children, CLIC, Cancer BACUP, the Christian Lewis Trust, Macmillan and Make-A-Wish Foundation (UK) Ltd. All of these voluntary organisations support children with cancer and their families across the UK. Indeed, amongst the 13 organisations mentioned by more than one centre (see Appendix 3), all were UK-wide organisations. However, amongst the 24 organisations mentioned by only one centre, these were largely locally based charities and organisations. Many centres thus valued locally based voluntary sector psychosocial support, however, this suggests that that the type and degree of support offered to families varied across the UK.

2.9.2 Psychosocial support service gaps

When asked to identify ‘gaps’ in psychosocial services within their treatment centre, staff highlighted a range of support services and areas. Key areas are reported below, with those most frequently noted discussed first (see also Appendix 3).

Psychology support
The provision of psychologists and the support they provide was the most frequently noted area where more support and resources were felt to be required. Indeed, just under half (11) of the centres identified this as a gap where additional resources were urgently required. Centres frequently had to share psychologists with other departments; as a consequence it was felt that families were not routinely referred to psychologists or did not have access to psychological support. The availability of routine support was clearly viewed as beneficial but currently unobtainable, as these comments demonstrate:

> ‘Dedicated psychology time to provide routine patient and family support from diagnosis. Currently, the psychologist is shared with nine other wards.’
>
> ‘Very limited psychologist availability – can only get input for specific referrals, so tend to only refer severe problems as the pressure of work in the psychology department precludes any other involvement.’

In addition, three centres also noted a dearth of psychological input within psychosocial assessments. Assessments could thus be partial, a factor which did not escape one centre:

> ‘More neuropsychological assessments to inform planning, advise parents and schools.’

Social work support

The important and diverse role that social workers (both local authority and voluntary, for example, Sargent) play was clearly recognised by the centres. Indeed, nine centres highlighted a dearth of social worker support as an area of key concern. Some of the comments included:

> ‘Very limited social work service.’
>
> ‘Statutory services are not often involved from social work as children with long-term illness would not be given priority due to major staff shortages locally.’

Four centres related their concern specifically to recent Sargent organisational changes and corresponding reorganisation and deployment of Sargent social workers in treatment centres. This was frequently perceived as a reduction of support and was succinctly summarised by one centre:

> ‘We only have one Sargent social worker as one left and has not been replaced due to financial problems with Sargent. This has had a high impact on the service. With only one social worker the minimal amount of support can be provided by her.’

This was clearly felt to have important implications for patients and their families with regard to the type and level of support received and also for health service staff in terms of their work loads.

Support for children, young people and families

Four centres, all of which provided separate accommodation for children and teenagers, reiterated the importance of support for teenagers. However, important gaps were felt to exist in the provision of appropriate services, especially in terms of activities available/provided for teenagers and the support of specialist youth worker/activity co-ordinators, as noted by one centre:

> ‘Need for a youth worker for older children/adolescents.’

In addition, one centre felt that more support and recognition should be provided for the partners of teenagers/young adults.

Support for parents was also raised as an area of concern. In particular, one centre suggested that more family support workers were needed to facilitate both practical and emotional support, the latter via parent support groups:

> ‘Family support worker to co-ordinate accommodation, transport, laundry difficulties etc, and to identify problem areas and help set up and lead parents groups.’

Beyond the nuclear family, two centres highlighted the importance of wider family support, especially for grandparents.

Support for survivors/long-term follow-up

Three centres raised this as an area of potential gaps; however, the comments made were rather vague. The needs of survivors were generally noted but specific areas of support were not indicated. For example, comments included:

> ‘Long-term follow-up.’
>
> ‘Longer-term rehabilitation needs of survivors.’

Communication

A lack of communication and co-ordination between centre staff and other professionals was noted as an area of concern by three centres. More specifically, it was felt that lines of communication were frequently inadequate amongst centre based staff and those working either out in the community or for different agencies. For example, one centre noted:

> ‘Need for better communication channels between school teachers and Macmillan nurses.’

Another suggested:

> ‘Debriefing sessions made more often to staff not based on wards, e.g. teachers and dieticians through better communication between sessions.’

Policies ensuring that information is passed on in a co-ordinated manner to relevant professionals were sought, especially when patients received treatment in different places.

It is also interesting to note that only two centres highlighted communicating information to families as an area of concern. Here, the two issues raised focused upon providing written information in a more accessible format to families and having easier access to interpreting and translating, as required.

Play and other therapies

Four centres stressed that either more play therapy time or resources were needed. For two centres, attention was focused upon the need to extend the provision of play specialist support beyond the hospital and increase their hours, as one centre noted:

> ‘No play specialist support for palliative care at home and for weekend support for families on the wards.’

In addition, two other centres felt it would be advantageous to follow-up play sessions with art or music therapy, which was currently unavailable.

> ‘Art or music therapy – trained personnel could follow-up any play concerns noted by the play team.’

Support for staff

The survey results showed that the provision of psychosocial support for staff varied amongst centres. However, six centres clearly felt that staff support was an area in need of more formal systems of regular, ongoing support, as one centre noted:

> ‘We do not have an organised system or policy for staff support and this is very important in this work.’

Indeed, recognising the important and yet stressful role that staff play, supporting families through a frequently traumatic and prolonged illness trajectory, highlights the need to provide good quality staff support. For one centre, a key area for improvement was providing counselling for staff who themselves act as counsellors:

> ‘Staff support should be offered to all staff – counselling support should also be provided for those who are counselling.’

2.9.3 Duplication between the statutory and voluntary sector

Only one centre identified an area of duplication between the statutory and voluntary sector within their centre. Concern was expressed around the issue of staff roles and boundaries with regard to social work and nursing support, particularly the support provided by Macmillan nurses. Here, a lack of clarity between health and social care with regard to issues of treatment and counselling was felt to be both confusing and counter-productive for professionals and families alike. This was succinctly summarised:

> ‘In my opinion, there are too many people all picking at the same cherry. This is confusing for families and often unhelpful with staff desperate to jump in first and then checking what has been done. It is very frustrating.’

2.10 Survey of key voluntary agencies

2.10.1 Survey methods

A postal survey of key voluntary agencies working with NHS Paediatric Oncology Treatment Centres in the UK was carried out to explore the psychosocial and practical support services provided for children with cancer and leukaemia and their families by the voluntary sector. A questionnaire was developed in consultation with the project steering group, with representatives from the paediatric oncology treatment centres and key voluntary agencies. This was approved by the Northern and Yorkshire Multi-Centre Research Ethics Committee and sent to five key agencies, which were identified both in the survey of the centres and by the steering group as the main agencies working with treatment centres:

- Cancer and Leukaemia in Childhood (CLIC)
- Candlelighters
- Macmillan Cancer Relief
- Sargent Cancer Care

- Teenage Cancer Trust (TCT)
- Christian Lewis Trust.

The questionnaire examined:

- The types of support services provided.
- The number and process of family referrals.
- Areas of service duplication and gaps in service provision.
- Co-ordination with the state sector.
- Future plans.

Questionnaires were completed by five of the six voluntary agencies and the results recorded on an *Access* database for analysis.

2.10.2 Survey results

Types of support services

Macmillan Cancer Relief reported very few psychosocial and practical support services for children. The charity had recently developed a new social care strategy, which prioritised support for carers and financial support as areas for service development. Financial support included the provision of patient grants for children as well as adults, which Macmillan intended to continue to promote in the future.

The remaining four voluntary agencies funded specialist posts within treatment centres and a range of support services based in the hospital and/or the local community. See Table 2.7 below. However, it should be noted that Candlelighters only serves St James' University Hospital in Leeds and the six local hospitals with which it shares care. All other agencies in the survey provided services on a UK-wide basis.

Table 2.7 Type of support provided by voluntary agencies

Type of support	*Agency providing support*
Medical staff	CLIC, Candlelighters, TCT
Social workers	Sargent, Candlelighters
Family Support workers	Sargent
Psychologists	Candlelighters
Play specialists	CLIC, Candlelighters, Sargent
Art Therapist	CLIC
Activity Co-ordinator	TCT, CLIC
Information	CLIC, Sargent, TCT
Hospital-based family support	CLIC, Candlelighters, Sargent
Home-based family support	CLIC, Sargent
Newsletters	Candlelighters, Sargent, TCT, CLIC
Domestic help	Sargent
Support groups	CLIC, Candlelighters, Sargent, TCT
Counselling	Candlelighters
Care grants	CLIC, Candlelighters, Sargent
Specialist equipment	CLIC, Candlelighters, Sargent, TCT
Leisure activities	Candlelighters, Sargent, CLIC
Adapted play equipment	Candlelighters, Sargent
Holiday breaks	CLIC, Candlelighters, Sargent
Sitting service	Sargent
Home from home accommodation	CLIC, Candlelighters, Sargent
Home based palliative care	Candlelighters, CLIC
Transport	Candlelighters, Sargent
Complementary therapies	CLIC, Candlelighters
Hospital-based terminal care	CLIC
Bereavement support	Candlelighters, Sargent, CLIC
Specialist adolescent units	TCT
Specialist adolescent conferences	TCT

Treatment centre staff funded by voluntary agencies included specialist medical staff, social workers, psychologists, family support workers, play and art therapists and activity co-ordinators. Services ranged from support groups and specialist equipment provided by all four agencies, to specialist teenager/young adult units and conferences provided solely by the TCT.

Asked to highlight important aspects of the ways in which their organisation works with statutory agencies to support a family, the following issues were raised:

- Providing specialist equipment at short notice, such as specialist car seats and medical equipment for home-based palliative care *(Candlelighters).*
- Funding core NHS staff to ‘be there’ for families at diagnosis, through treatment and palliative care, and beyond *(CLIC).*
- Providing financial support *(CLIC and Macmillan).*

- Referring patients to the statutory benefits agency *(Sargent).*
- Developing a patient and family support service *(TCT).*

The number and process of family referrals

Data on the approximate number of children and young people and their families reached through the agencies' work in the last year are reported in Table 2.8 below:

Table 2.8 Number of children/young people and their families reached

Name of agency	*Number of families*
Candlelighters	1900
CLIC	2000
Macmillan	150
Sargent Cancer Care	3500
TCT	2000

Invariably families were referred to the voluntary agency by staff from the treatment centres.

Areas of service duplication and gaps in service provision

No areas of duplication were identified by voluntary agencies. However it was noted that the voluntary sector funds a number of core NHS staff and buildings. This was reported as consuming resources that would otherwise fund services with ‘added value’.

In relation to gaps in service provision, the following gaps were noted:

- *Information*
  - information about the support available
  - accessible information about specific diseases, common problems and practical solutions
- *Social and emotional support*
  - support for the care of siblings, especially during periods of intense treatment
  - family/partner support to prevent relationships from breaking down
  - practical and emotional support for teenagers
- *Financial support*
  - paid parental leave
  - financial support for teenagers
- *Transitions*
  - co-ordinated school re-integration for both patients and siblings
  - transitional care.

In addition the gap created by cuts in Sargent Cancer Care’s hardship grants was noted, with non-resident parents particularly hard hit by cutbacks in travelling expenses.

Co-ordination with the state sector

A number of suggestions were made regarding ways that statutory and voluntary agencies could better co-ordinate their roles in providing care and support for children and young people with cancer and their families. These included:

- *Funding*
  - discussion between sectors to clarify who and what both sectors are prepared to fund
  - partnership funding with government to produce enough resources to meet wide-ranging needs
  - consider funding requirements to meet agreed objectives and standards
  - review funding sources and potential sources
- *Information*
  - producing a comprehensive database for staff of what funding is available and from where
  - developing an alliance of voluntary and statutory organisations offering cancer services to children through which information could be exchanged and problem-solving could be brainstormed
- *Setting standards*
  - setting national standards for all aspects of care and support
  - identifying a standard and analysing gaps
  - agreeing objectives and 'ideal' standards
- *Collaboration*
  - discussion between sectors to prioritise needs
  - collaborating on projects
  - sharing best practice

Future plans

With regard to future plans two agencies, CLIC and Sargent Cancer Care, were engaged in strategic reviews to inform future service development. CLIC commissioned this research project in order to ensure that future service development would be informed by up-to-date research on children's and families' needs. Candlelighters had recently introduced an emergency 'get out of hospital' payment for families with no transport where there was an unexpected window in treatment. Macmillan reported that they would continue to promote their patients grants as being available to children. The TCT would address regional priorities providing this dids not impinge on their core objective of building more separate teenage units.

2.11 Overview of NHS treatment centre and voluntary sector psychosocial provision

The results of the postal surveys to NHS paediatric treatment centres and key voluntary agencies provided a comprehensive overview of current UK wide patterns of psychosocial service provision available to children and young people with cancer or leukaemia and their families. Indeed, the positive survey response from the treatment centres may indicate the value that staff generally attach to psychosocial support and its role as an established part of centre service provision.

The voluntary sector questionnaire, although completed by a small number of agencies (five), represented organisations that are well established and respected as key providers within paediatric oncology. The data provided by the voluntary sector questionnaire in many ways complements the NHS centre survey. However, it is also apparent that voluntary agencies play an important role in psychosocial service provision in their own right. For example, CLIC and Sargent Cancer Care fund both hospital and community based staff posts, including specialist medical staff, social workers and play specialists/co-ordinators. Voluntary agencies and the staff they fund provide family support, both social and financial, and also focus upon more specialist and targeted services, such as the Teenage Cancer Trust's work in developing teenage cancer units. Despite this, it is also important to recognise that the voluntary sector does not and should not work in isolation from the statutory sector. Indeed, the voluntary sector survey highlighted the need for more collaboration and joint strategic planning with the statutory sector in order to ensure the best use of resources and service provision for families.

The results of the centre survey will be discussed in more detail and placed in a wider context, via comparisons with the family survey data exploring parents' and children/young people’s experiences of psychosocial support, in the concluding chapter. However, five key areas and issues have clearly emerged from the NHS centre survey, these can be summarised as follows:

- There was no standard provision in the number of staff providing psychosocial support. Staff ratios did not appear to be related to discernable factors such as the number of new patients per year or age of patients. Some areas of staff provision were poor, this was apparent in the shortage of psychologists and counselling services.

- Family support may be common practice but the focus was mainly upon the child/young person with cancer and their parents. Support for other family members may be recognised but was less frequently provided. For example, at some centres family accommodation did not include accommodation for siblings or grandparents.

- Written information for families was usually provided by all centres. However, provision of alternative forms of information, such as audiovisual and online information or information specifically for children/young people, was less frequent.

- The needs of teenagers were clearly recognised by centre staff and most centres provide some form of teenage facilities, with teenagers best served at Teenage Cancer Trust Units. However, standards and degrees of provision varied across the UK, especially at centres without separate teenage facilities.

- There were generally very few standard practices and procedures across centres. This was most clearly demonstrated in areas of transition, such as hospital to home, returning to school, moving from paediatric to adult services and long-term survivorship, and evolved from an informal/formal divide. Centre practices were rarely formally recorded in writing, this left them open to interpretation and different modes of implementation.

Chapter 3. Interviews And Focus Groups With Parents And Children/Young People

3.1 Methods

The second phase of the research focused upon individual and group interviews with children and young people with cancer and leukaemia and parents of children with cancer or leukaemia at different stages of the illness trajectory. The aim of the interviews was to highlight key research issues surrounding psychosocial support and service provision. These issues would then be used to inform and guide the development of the family questionnaires (stage three of the research), as it was recognised that parents and children may have different ideas and priorities from professionals, issues that the stage one centre survey had not highlighted. This stage of the research was thus not intended, and should not be read as, an independent piece of qualitative research but rather as a key component of the development of family questionnaires. Indeed, developing these questionnaires provided an opportunity to explore whether the support issues raised by a relatively small sample of parents and children/young people are of general concern amongst a broader sample of parents, children and young people experiencing cancer or leukaemia.

Whilst recognising the sensitivity and diversity surrounding psychosocial support services for children, young people and their families, it was decided that interviews would not include participants whose first language is not English or bereaved parents. This was due to methodological and practical reasons; methodologically, the complex issues facing both groups requires separate research and practically, the researchers did not have the time or resources to interview groups separately or work with interpreters.

3.1.1 Developing the topic guides

Focus group topic guides were developed for parents and children/young people drawing upon the centre survey questionnaires and suggestions from the project advisory group. The parents’ topic guide focused upon three main areas:

- Psychosocial and practical support services – here, the aim was to initially clarify the terms, and scope of, psychosocial and practical support services and then to explore what care and support services had been provided for parents, what they felt they needed and what could be improved.
- Life changes – parents were asked to consider changes that had occurred in their lives as a result of caring for a child with cancer or leukaemia and the support needed to cope with these changes; once again, highlighting areas of good and poor provision.

- Information – parents were invited to consider how they would like to receive, and how they would like other family members to receive, information.

Parents were initially asked to discuss issues and share ideas in small groups or pairs and then feedback to the group as a whole. To aid discussion within each of the three areas, parents were given sheets of key issues that had been gleaned from the centre survey and previous literature. These acted as an important ice breaker and a quick and easy mechanism to prioritise or add new ideas. The parents' topic guide was piloted with five parents. Minor amendments were made in light of parental feedback.

The children and young people's topic guide was similarly organised around three activities:

- Identifying key issues – children and young people were asked to consider positive and negative events that they had experienced during their illness and identify support that had been or was helpful or unhelpful.
- Spider diagrams – participants were asked to draw a personal spider diagram of support received and valued.
- Bags of money – children and young people were given the opportunity to allocate five bags of money to areas of support they considered important to continue funding or develop further.

Participants were encouraged to consider their feelings at different stages of the illness trajectory, such as diagnosis, treatment, staying in hospital, being at home and returning to school or college. Children and young people were also given the option of working in small groups, pairs or individually, writing or drawing their ideas and then feeding them back to the group. For those who did not want to write, a researcher was available to transcribe. Once ideas had been collected, the group collectively graded them, via a traffic light system (green = good, amber = ok and red = poor). To aid discussion, each participant was given a set of stickers depicting a range of situations and issues, such as 'making new friends', 'having someone to talk to' and 'being with my family'. The topic guide was piloted with three children (aged 10-13) and three young people (aged 14-18). The language used and degree of support given was adapted to the children's age. Once again, slight modifications, in terms of topic guide content and interviewer approach were made in light of participant comments.

3.1.2 Recruitment

Recruitment for focus group participants was sought from eight diverse NHS treatment centres. The centres were Birmingham, Bristol, Glasgow, Great Ormond Street, Leeds, Manchester, Middlesex and Sheffield and thus reflected urban and rural populations, a range of specialisms and care delivery (including shared care) and different age ranges. A small but diverse sample of 36 parents and 24 children and young people was sought. The sample was subdivided into 10 smaller groups, stratified by age and stage of treatment.

Table 3.1 Focus group recruitment targets: centre breakdown

Group type	*Number of members*
Parents of children 0-5 years, active treatment	6 parents*
Parents of children 0-5years, post treatment	6 parents
Parents of children 6-11 years, active treatment	6 parents
Parents of children 6-11years, post treatment	6 parents
Parents of young people 12-18 years, active treatment	6 parents
Parents of young people 12-18, post treatment	6 parents
Children 10-13 years, active treatment	6 children
Children 10-13 years, post treatment	6 children
Yong people 14-18 years, active treatment	6 young people
Yong people 14-18 years, post treatment	6 young people

***** Parents were asked to select one representative from their family

Each centre was then allocated either a group or two groups of parents, children or young people to recruit. Three separate information packs were developed for parents, children and young people. Each pack contained a project information sheet, consent and personal details forms. Recognising that recruitment may be problematic each centre was asked to send an information pack to at least double the number of respondents needed for each sub-sample. So, for example, if six participants were wanted, at least twelve packs were sent out. Some centres ultimately sent out additional information packs.

Recruitment was slow and uneven amongst centres. Ultimately, the project recruited 31 parents and 15 children and young people receiving or having received treatment from the eight centres, as detailed in Table 3.2.

Table 3.2 Sample of parents, children and young people interviewed *

Category	*No interviewed*
Parents of children 0-5 years in active treatment	5
Parents of children 0-5 years, post treatment	6
Parents of children 6-11 years in active treatment	2
Parents of children 6-11 years, post treatment	6
Parents of children 12-18 years in active treatment	5
Parents of children 12-18 years, post treatment	7
Children 10-13 years in active treatment	3
Children 10-13 years, post treatment	4
Young people 14-18 years in active treatment	3
Young people 14-18 years, post treatment	5
Total	**46**

***** includes pilot interviews with parents and children/young people

Initially, the aim had been to conduct focus groups with parents and focus groups with children and young people. However, a number of practical issues and recruitment problems led to a more varied approach. The three key problems encountered were:

- Families off treatment were more responsive than those on treatment. This is understandable due to the emotional, caring and practical demands that children/young people and their parents face during treatment.
- At one centre, there was a very high non-response rate. There was an absence of child/young person volunteers and only one parent volunteered; the centre felt this was a reflection of families generally facing research fatigue.
- Lakeside summer activity holidays had initially been suggested to both recruit and conduct the child/young people group interviews. However, after a great deal of time and negotiations this was unsuccessful.

3.1.3 Procedures for focus groups and interviews

In response to parental and child/young people preferences and circumstances, interviews were conducted in a group format, individually or by the telephone. The focus group topic guides were adapted for the individual and telephone interviews, for example, a summary topic guide was sent to participants prior to telephone interviews. Telephone interviews were only conducted with parents.

Eight focus groups were conducted with between three and five participants, plus eight individual interviews and seven telephone interviews. Although a small sample, a range of parents, child and young people were interviewed, encompassing, as the following table indicates, children/young people at different stages of the illness trajectory (on and off treatment) and different age ranges:

Table 3.3 Types of Interview

Pilot focus groups	1 parents' group (n= 5) 1 children's group, 10-13 years (n= 3) 1 young people's group, 14-18 years (n= 3)
Focus groups	4 parents' groups (n= 15) 1 children's group, 10-13 years (n= 3)
Individual face to face	Parents (n= 4) Children, 10-13 years (n= 1) Young people, 14-18 years (n= 5)
Telephone	Parents (n= 7)

The group interviews were conducted by two researchers and held in a range of venues, such as hospital meeting rooms, family based accommodation (for example, Pact House) and a local arts centre. One researcher conducted the individual and telephone interviews. The individual interviews took place mainly in participants' homes; however, two were held in hospital meeting rooms.

Prior to each interview, written consent was gained from each participant and parental consent for those under 16 years. Before each interview proceeded, consent was re-established and the researchers discussed issues such as confidentiality, and the importance of participants feeling able to stop the interview whenever they wanted and only answer questions that they are comfortable with. At group interviews, the researchers suggested a list of basic ground rules that participants should adhere to, such as respecting other people's views and listening, and then invited group members to add to the list if they wished. Appreciating the potentially sensitive and stressful nature of the interviews, post interview support was established for participants. At each interview, participants were handed a support card with the contact details of the researcher and a relevant Sargent social worker, previously briefed about interviews. With participant consent, the interviews (group, individual and telephone) were tape recorded and transcribed.

3.2 Results

As noted previously, the purpose of these interviews was to identify themes and issues that had not been included in or raised by the treatment centre survey but were regarded as important by parents, children and young people. The results reported here are a summary of the key additional points that helped develop the subsequent parent and child/young people questionnaires.

3.2.1 Interviews with parents

Facilities and practical issues

Preparation for admission

Parents highlighted both practical and emotional support needs. Practically, they felt it would be useful if hospitals provided a checklist of key items that their child (and they) would need in hospital. More help preparing families, both parents and child emotionally for staying or visiting hospital would also be welcomed. Suggestions included, a home visit from a member of hospital staff providing an opportunity for parents to discuss any fears or concerns and an age appropriate video for children. Here, it was felt important to address the potentially frightening experience of seeing other sick children and complex machinery.

Practical support

Parents who had stayed with their child in hospital raised childcare as an issue, especially the problem of finding the time and opportunity to have a break from caring for their child. One suggestion was to employ designated parent support workers who would effectively relieve parents for a while. Parents also felt a sitting service for other family dependents, such as siblings or grandparents would be useful. The difficulties of caring and trying to maintain domestic routines was also noted, particularly, at key points in time, such as when a child returns home and requires a sterile environment if they are neutropenic. More help with domestic tasks would be welcomed; suggestions included the provision of or subsidising an agency cleaning service. Support was also felt to be lacking with regard to other practical issues, such as organising transport or equipment, especially wheelchairs. Parents felt a designated patient co-ordinator taking responsibility for these would be helpful.

Facilities requiring improvement

Parents raised a number of hospital facilities that they would like improved. The three that came to the fore were: providing age appropriate facilities for teenagers; more computers, activities and entertainments for children and teenagers, once again, it was important that they were age appropriate; and improving hospital décor - bright, cheerful and welcoming hospital wards were valued.

Hospital food

Poor quality and unappetising food was continually noted with subsequent effect upon a patient’s recovery and the difficulties and financial costs parents frequently faced trying to supplement hospital food. Improvements suggested focused upon: developing business sponsorships/partnerships; and providing alternatives for parents, such as, freshly cooked meals at CLIC/PACT houses or improved kitchen facilities for parents to use, for example, microwaves and more storage. Some hospitals provide family canteen discounts; however, parents were not always informed of this, especially at the start of treatment, clearer information that is more consistent was thus wanted.

Training

The value of basic training for parents in medical procedures was recognised, some parents welcomed more training, especially when their child returned home.

Holidays

The importance of organised family holidays, frequently provided by the voluntary sector, was noted. Parents valued an opportunity for the whole family to go away together in a supported environment, i.e. with a hospital nearby or medical staff easily contactable, without the fear of a late cancellation (due to a relapse) resulting in financial loss. Parents also recognised the importance of holidays for children without parents, providing both a break for the child and parents. However, not all families knew of these holidays or had been offered them, more consistent information was also required.

Psychosocial support services

Sibling, grandparents and other family members

It was apparent that the existence and role of siblings, step-parents and step-siblings are an important consideration within family relationships and support networks. In addition, the value and role provided by ‘other’ family members beyond the nuclear unit, such as grandparents, uncles and aunts was also noted.

The need to provide more psychosocial support for ‘other’ family members, particularly siblings and grandparents was highlighted. Parents particularly wanted more targeted information and support groups for siblings and grandparents and more generally, the availability of ‘someone to talk to’ for them, if and when needed. Many parents felt that the provision of ongoing backup support was severely lacking for these family members.

Parental support

Although many parents recognised and appreciated the emotional support received from the treatment centres and their staff, such as doctors, nurses and social workers, a number of service gaps and suggested improvements emerged. Some parents wanted more pro-active emotional support across the illness trajectory, with professionals initiating and explaining the support available rather than waiting for parents to ask for help. Attention was focused upon social worker time and input for some, however, this was not the case for all; other parents clearly did not want social worker support. In addition, many parents recognised, even if they had not experienced, the value of a ‘key worker’ providing a vital point of contact, information signposting and liaison with other services and their providers. Less formal support was also valued, in particular, low key counselling and advice that key workers could provide. Some parents took this a step further and suggested the potential value of a flexible ‘cancer buddy’ system, providing informal support for parents, perhaps from other parents who have similarly experienced childhood cancer or leukaemia and undertaken advice/counselling training.

A small number of parents would also have welcomed more practical and emotional help in dealing with behavioural problems that emerged during the course of their child's illness, such as home visits and developing behaviour programmes.

Personal issues

Parental interviews highlighted the importance of relationship changes and developments, this was particularly pronounced amongst spousal/partner relationships, and the dangers of relationship breakdown. It was felt this is an issue parents should be alerted to (i.e. the fact that relationships can and do change over the trajectory a child's illness) and have an opportunity to discuss, if desired. Hence, accessible and well-publicised couples counselling was suggested, alongside the need for hospital staff to be more aware and sensitive to familial relationship changes and stresses.

In addition, a small number of parents noted personal psychological and medical effects of coping with their child's illness, such as being prescribed anti-depressants by their GP.

Information and financial issues

Parents' preferences

Parents' preferences and requirements as to how information should be provided invariably differed, as information is a very personal issue and needs vary across the illness trajectory. Despite this, it was apparent that parents generally preferred verbal information, supplemented by written information. The gaps that emerged included a need for more information at certain points in time, such as end of treatment and also specific information, as many parents frequently adopted the role of 'treatment co-ordinators' and thus felt they needed to know more about their child's medical routines.

The potential value of the internet was recognised, but many parents also felt rather overawed and frightened as to what information they may receive. Help was required negotiating the internet and controlling the quality and scope of information received. One suggestion was a list of sites recommended by professionals or those working in the field.

Information for others

Information for children was generally valued and a range of sources welcomed, such as videos and age appropriate books/leaflets, moving beyond traditional verbal information. As noted previously, more information for other family members (such as siblings and grandparents) was also wanted.

Financial

Discussions illustrated the importance and impact that financial changes and fluctuations can have upon families during the illness trajectory. This was most marked with regard to loss of parental earnings due to changes in hours of employment, frequently to accommodate caring responsibilities, and increased expenditure, such as travel, family accommodation when a child stays in hospital and meeting the requirements of special diets. In addition, benefits and grants were also raised. For example, the importance of parents receiving information regarding their eligibility for and help with applying for state benefits, such as Disability Living Allowance. Other forms of financial aid, such as charitable grants were also valued, in particular, the Family Fund.

Transition periods and issues

Hospital to home

Parents who had experienced an 'end of treatment meeting', usually with a nurse and/or social worker, prior to their child's return home felt that this had been a useful and productive forum to discuss a range of relevant issues or voice parental concerns.

Community out of hours nursing, such as support during the evening and at weekends, was highlighted as an important gap that needed to be addressed.

Returning to school

Parental experiences of and need for support during their child's transition back to school varied. However, where more support was wanted, the need for educational co-ordinators was noted, ideally, a designated person co-ordinating the transition between hospital staff, the school and family, liaising with and making sure that key information was passed on to relevant people.

Physical changes

Although not specifically a transition issue, physical changes for their child as a result of cancer or leukaemia raised a number of parental concerns. For example, in relation to hair loss, some parents noted the poor quality and limited styles available via the NHS wig service. A more varied selection of wigs and provision for a subsidised service would be welcomed. Fertility is an extremely broad and complex issue, however, some parents touched upon the importance of gender appropriate consultants being available to discuss sensitive issues with young people, for example, mothers of female teenagers highlighted menstruation. With regard to future fertility, the importance of provision of services for sperm banking and egg harvesting was also recognised.

3.2.2 Interviews with children and young people

Facilities and practical issues

Staying In hospital

Discussions with both children and young people demonstrated that a number of key areas are valued. These include bright and cheerful decorations, as they make patients feel welcome and create a more ‘homely’ atmosphere. Similarly, the opportunity to take personal belongings into hospital, such as photos and toys, and place these by one’s bedside was valued. Flexible rather than rigid visiting hours, with family and friends being able to visit as and when they wanted, were also welcomed. This was particularly important to those with family and friends travelling long distances or working shift hours. The importance of privacy and spending time by oneself was also noted, for some young people having one’s own room or at least some form of partition around the bed was highly valued.

Opportunities to spend time off the ward in a patient lounge or common room were also welcomed. Amongst the younger children, play spaces were particularly important, both in and outdoors. Indeed, great importance was attached to the quality and quantity of leisure facilities and activities available in order to combat boredom. Having to share televisions and computer games with others was a key criticism, due to the varying tastes and age preferences of children and young people. Hospitals providing a range of age appropriate facilities, both in terms of accommodation and leisure activities, were valued. Teenagers especially felt that activities were frequently child orientated, for example the prominence of Disney videos. Those who had experienced age appropriate facilities, such as a teenage lounge clearly valued them. In addition, the importance of disability specific toys was recognised, for example, adapted computer games or jigsaws for children who are partially sighted.

Hospital food

As in parental interviews, hospital food was a source of criticism and concern. Children and young people wanted better quality and more variety in terms of how food was offered. Suggested improvements included: a more child friendly rather than adult orientated menu, for example, pizza and fun foods, and more flexible meal times, having one breakfast, lunch and dinner serving was not welcomed. Being able to eat as and when one felt hungry was stressed; having more snack machines was felt to be one way to overcome this problem.

Hospital school

Children and young people wanted flexible hospital schools in terms of hours and where they attended (i.e. the child going to the school room or the teacher coming onto the ward). However, some teenagers felt that hospital schools were frequently child rather than teenage orientated, particularly in terms of educational support provided.

Holidays

As in parental interviews, the importance of organised family and individual holidays was noted. Family based holidays were welcomed as an opportunity for the whole family to escape the routines and rigours of hospital treatment and begin to be a ‘normal’ family again. For those young people who had experienced a holiday with other children/young people with cancer or leukaemia, this was seen as a positive experience, an opportunity to spend time with others in similar circumstances and boost one’s confidence. However, as with parents, not all the children/young people interviewed had been offered such holidays.

Psychosocial support services

Support from parents and other family members

Throughout the interviews, it was clear that relationships with kin, both nuclear and extended, were extremely important to the children and young people in terms of their experiences of and needs for psychosocial support. Children and young people continually highlighted parental and sibling relationships, many noted the importance of grandparents, and some discussed step-parents and the value of local community support.

Whilst staying in hospital, especially for extended periods, both children and young people, irrespective of age, stressed the importance of parental support. Parents, especially ‘Mum’, being able to stay at or near the hospital was important, as they were felt to provide both emotional and practical support. Emotionally, children and young people valued having someone they knew and felt comfortable with to talk to. Practically, Mum also provided a vital caring role, as it was recognised that nursing staff were extremely busy.

Peer support

Retaining contact with school peers was also highlighted throughout the interviews, especially when not attending school. Hence, the importance of hospitals welcoming peers and, as noted earlier, the provision of flexible visiting hours. Talking to peers or their families who had experienced or had knowledge of cancer was similarly valued. Support groups received a mixed response, some children and young people were very positive and welcomed the support they offered, whereas others viewed them with caution. However, as noted above, the general idea of talking to others who ‘understood’ was welcomed. Informal support groups were preferred with leisure activities a central component, such as going bowling or to the cinema. It was also felt that membership should be relaxed, with young people tapping in and out of groups as and when they wanted. Hospital based meetings were viewed as too formal and not always convenient, due to problems of distance. More locally based meetings were thus suggested, with alternating venues in order to meet the needs of as many young people as possible.

Professional support

Some children and young people had experienced social worker support, whereas others had not and did not want to talk to social workers. Amongst those who had seen a social worker, the importance of continued support on return home was noted, as were the benefits of social workers taking a pro-active approach, initially contacting families.

Although most children and young people interviewed had not experience counselling, the idea of being given information and a choice as to whether or not they would like to receive counselling was welcomed.

Information and financial issues

Receiving information

The importance of staff, particularly doctors talking directly to children and young people was clear. Honest information, explained in a clear and understandable manner was wanted for children, this involved avoiding complicated medical terminology. Teenagers in particular noted the importance of choices, for example being given the option of speaking to staff without parents present, even if not taken up. As with parents, the degree of and how information should be received varied, however, cancer specific written information was noted. Those who had received a treatment plan felt this was useful. The potential of the internet was also recognised but more guidance was wanted.

Preparation for treatment

Toys, especially for young children, were recognised as a key preparation tool, aiding understanding and helping to relieve anxiety. Older young people wanted more staff tips and practical suggestions on how to make treatment more bearable and additional information concerning possible side effects. Once again, an opportunity to make choices, however small, was stressed, such as the ordering of routine procedures.

Shared care

Problems of information sharing were noted, such as hospitals presuming that another had passed on information to family members. Better co-ordinated information amongst shared care centres was wanted.

Financial

Amongst the small number of young people (16 plus years) able to receive state benefits in their own right, the importance of clear financial information and practical help filling in forms was recognised and more help welcomed.

Transition periods and issues

Hospital to home

Older young people, especially those with physical disabilities, highlighted the importance of discussing with hospital staff how to cope on return home. Equipment was a key area, ensuring adequate home provision. Staff advice and teaching self medication skills (cleaning lines and injections) was welcomed both for parents and by some of the young people themselves, as this led to increased autonomy at home and reduced dependence on community professionals, such as community nurses.

Independence issues and changed family relationships, particularly with parents and siblings were also mentioned, for example, how to develop or re-establish one's independence at home if one is still physically dependent on others. Opportunities to discuss these complex issues were viewed as important.

Returning to school
The key theme on return to school was ensuring that information was circulated to all relevant parties in a logical and timely fashion with hospital staff taking a lead role. The importance of teachers being well informed was stressed. Children and young people valued and felt their transition back to school was eased when teachers understood their cancer, its side effects and accommodated any specific needs. For some, preparing and supporting peers was also valued, especially in terms of physical changes such as hair or weight loss, however not all welcomed this.

Home tuition
For those who had experienced home tuition, problems focused upon tutors lack of knowledge and understanding of cancer (both general and specific), and the lack of educational provision for older young people facing public examinations. Suggestions included more information for home tutors and matching tutors more closely to young people's educational needs.

Physical changes
The experience of hair loss raised varying opinions, some children and young people felt too much time was spent discussing hair loss, whereas others wanted more preparation and explanation of the different available options, such as having one's head shaved, hair cut or taking no action.

Fertility issues had been discussed with hospital staff by a small number of young people. These young people were generally pleased that issues such as pregnancy and sperm preservation had been raised, but felt it was important to do this in a gradual manner, giving young people the option to discuss issues without parents present.

3.3 Developing the family questionnaires

The results of group, individual face-to-face and telephone interviews highlighted that parents and children/young people share a number of valued areas of psychosocial support and, similarly, have concerns surrounding some key issues. For example, within the area of hospital facilities, both parents and children/young people stressed the importance of providing age-appropriate facilities and leisure activities for children and young people, especially teenagers. Practically, the importance of creating a homely and welcoming atmosphere via bright and cheerful decorations was noted, as was improving hospital food, which was viewed as frequently inappropriate to patient needs and of poor quality. In terms of information, although, as one would expect due its personal nature and families' different circumstances, parents and children/young people diverged as to the degree of and when information was required, more medically based information was wanted. In addition, the internet as a potential source of information was also recognised but simultaneously viewed with caution, more help and guidance on navigating the world wide web was felt to be needed.

With regard to personal relationships, both parents and children/young people felt that relationships with partners and kin can change over the course of the illness trajectory and would thus welcome more help and guidance, particularly opportunities to discuss these issues. The importance of family and escaping the rigours of cancer treatment was similarly stressed through the positive response to free organised family holidays in a supportive environment. The advantages of individual holidays for children and young people were also noted.

Moving off treatment and returning home can be a very uncertain time for children, young people and parents alike. In order to ease the transition back to school, more help was wanted ensuring that information is circulated to relevant parties in a logical and timely manner. Similarly, thinking about the future can be stressful, future fertility, although complex was recognised as an important issue to consider, especially fertility preservation.

In contrast, the interviews also demonstrated that there are areas and issues of divergence between parents and children/young people, reflecting, as one would expect, different perspectives and life experiences. For example, parents recognised the importance of more organisational and family wide issues, such as increased domestic support, specifically childcare and cleaning provision, and support service co-ordinators, such as professionals acting as key workers or a more informal system of 'cancer buddies'. In contrast, children and young people tended to focus upon more socially based and perhaps immediate issues, such as the importance of peer support throughout the illness trajectory and the quality and quantity of leisure activities provided by hospitals.

The results of the interviews thus indicate that although the survey of NHS paediatric oncology centres examined many important areas of psychosocial support, there are a number of additional areas and issues that were clearly prioritised by parents and children. The interview sample may have been small but it was varied, encompassing children and young people on treatment, off treatment and long-term survivors and similarly, parents of children of differing ages and stages of the illness trajectory. The results of the parents and children/young people's interviews were collated together and used as a foundation, alongside the centre survey, to develop two comprehensive questionnaires, one for parents and one for children and young people. The parents' questionnaire addressed a wide variety of support and service issues, whereas the children/young people's questionnaire centred upon a smaller and more focused range of age appropriate issues.

Chapter 4. The Family Survey

4.1 Family survey methods

Drawing upon the findings of the stage one centre survey and the stage two focus groups and individual interviews, two questionnaires were developed – one for parents and one for young people aged 10 years or over – to find out what services and support would best meet families' needs (see Appendices 7 and 10).

Families from one treatment centre - nine parents and four young people piloted the questionnaires and in light of their comments, and suggestions from the project steering group, minor amendments were made and a final draft produced. Ethical approval for the questionnaires was then obtained from the Northern and Yorkshire Multi-Centre Research Ethics Committee (MREC).

In order to safeguard patient privacy and comply with the Data Protection Act, questionnaire packs were distributed to families via their treatment centres. Packs comprised a parent's and a young person's questionnaire with reply paid envelopes, corresponding information sheets and covering letters – see Appendices 6 and 9.

Eleven centres were selected to provide a mix of northern and southern locations; metropolitan, urban and rural environments; ethnic diversity; and centres sharing care with other hospitals and centres delivering care at a single site. However when these eleven centres were approached for help recruiting families, four (Birmingham, Leicester, Middlesex and Southampton) declined to take part due to staff shortages and tight project deadlines. In accordance with the ethical approval obtained from MREC under the no local researcher arrangements, the local research ethics committees of those centres agreeing to provide assistance were all sent a copy of the MREC approval letter and their local NHS management was informed about the research.

With the aim of receiving 300 responses, 560 families were sent questionnaire packs by the seven remaining centres. Each centre was asked to select a sample of 80 families equally spread, as far as possible, across three age groups (0-5 years, 6-11 years and 12-18 years) and three treatment stages (on treatment, off treatment and five years post treatment). See Table 4.1 below for composition of the sample who were sent packs.

Table 4.1 Stage 3 centres sample

Centre	*0-5 years*		*6-11 years*		*12-19 years*		*Overall*
	On	*Off*	*On*	*Off*	*On*	*Off*	
Bristol	15	5	10	18	15	17	80
Glasgow	8	10	8	23	8	23	80
GOS	13	14	15	13	2	23	80
Leeds	14	13	13	14	12	14	80
Liverpool	16	11	16	12	8	15	78
Manchester							77
Pendlebury	*14*	*13*	*14*	*13*	*0*	*0*	*54*
Christie	*0*	*0*	*0*	*0*	*7*	*16*	*23*
Sheffield	17	14	14	10	10	20	85
TOTAL	**97**	**80**	**90**	**103**	**62**	**128**	**560**

After two weeks, non-respondents were sent a reminder letter with replacement questionnaires. Following this, if a centre's response rate from parents was less than 50 per cent, a final reminder letter was sent after a further two weeks.

Questionnaires were returned by 303 parents and by 112 young people. This represents a response rate from parents of 54 per cent. The response rate from young people based on the number of parents (n= 127) who responded with children aged 10 years or over (i.e. with children eligible to take part in the survey) was 88 per cent. See Tables 4.2 and 4.3 below for the composition of the sample of respondents.

Table 4.2 Parents' responses compared with centres sample (broken down by age, whether on or off treatment, and treatment stage and age group)

	Centres sample % (n=560)	*Achieved Sample % (n=303)*
Treatment stage:		
On treatment	44.5 (249)	43.9 (133)
Off treatment	55.5 (311)	56.1 (170)
Age group:		
0-5 years	31.6 (177)	33.3 (101)
6-11 years	34.5 (193)	33.0 (100)
12-19 years	33.9 (190)	33.7 (102)
Treatment stage and age group:		
0-5 years on treatment	17.3 (97)	16.8 (51)
0-5 years off treatment	14.3 (80)	16.5 (50)
6-11 years on treatment	16.1 (90)	15.8 (48)
6-11 years off treatment	18.4(103)	17.2 (52)
12-19 years on treatment	11.1 (62)	11.2 (34)
12-19 years off treatment	22.9 (128)	22.4 (68)

The pattern of achieved responses is very similar to the pattern of the sample who were sent questionnaires, indicating that the achieved sample is representative of those sent questionnaires.

Table 4.3 below compares the composition of responses from children and young people with responses from parents. Again very similar patterns were found.

Table 4.3 Children's responses compared to parents responses

	Parents' response % (n=127)	*Children's response % (n=112)*
Treatment stage:		
On treatment	34.6 (44)	30.4 (34)
Off treatment	65.4 (83)	69.6 (78)
Age groups:		
10-12 years	35.4 (45)	33.0 (37)
13-19 years	64.6 (82)	67.0 (75)
Treatment stage and age group:		
10-12 years on treatment	10.2 (13)	8.9 (10)
10-12 years off treatment	25.2 (32)	24.1 (27)
13-19 years on treatment	24.4 (31)	21.4 (24)
13-19 years off treatment	40.2 (51)	45.5 (51)

4.1.1 Analysis

Data from the questionnaires were recorded in an *Access* database and exported to *SPSS* for statistical analysis. Not all questions were fully completed by all respondents, but generally the information provided was comprehensive. Frequencies of response categories were analysed for all questions.

Unmet need was classified as respondents reporting that the service was needed but not provided or that provision was unsatisfactory (on parent questionnaire) or that they were not provided with a service needed or were unhappy with provision (children and young people's questionnaire). For the purposes of this report, key areas of unmet need are defined as areas where over 40 per cent of the sample report unmet need. High levels of unmet need, where unmet need is over 35 per cent, are also highlighted if these levels form part of the pattern of unmet need found overall.

In addition data were analysed in relation to satisfaction: a high level of satisfaction is defined 70 per cent or over of respondents reporting that they were satisfied or very satisfied (parents), and happy with provision or found it helpful (children and young people).

These data are reported across the whole sample. Differences in unmet need between age groups, treatment groups and age by treatment groups were analysed using chi-square tests, in order to ascertain whether certain areas of unmet need were affected by age or treatment stage. Areas showing a high level of unmet need for a specific group, where differences between groups were significant at $p < 0.05$, are also reported.

Finally, where a particular service is only relevant to a small sub group of the total sample (such as interpreter and translation services), unmet need and high satisfaction are also examined in relation to actual need, that is the number of respondents indicating that provision is needed.

4.2 Results of the parent questionnaire survey

The parent questionnaire (see Appendix 7) was completed by 303 families. The results are reported in nine sections based on those used in the questionnaire. In general, parents were asked to indicate if a particular facility or service was not needed, needed but not provided, or, if provided, how satisfied they were with this facility or service on a scale of one to five. As noted earlier, results are reported on key and high areas of unmet need and areas of high satisfaction for the sample as a whole or for particular sub-groups. All the data are presented in tables in Appendix 8.

4.2.1 Family Background and Employment (Sections A and J)

The first and last sections (A and J, here combined) asked parents for background information on their family, their employment and their child's illness and treatment.

Amongst the 303 families who completed the questionnaire, there were equal numbers in the 0-5 years (33 per cent), 6-11 years (33 per cent) and 12-19 years (34 per cent) age groups. Fifty-six per cent of responses were from parents of boys (56 per cent) and 44 per cent from parents of girls (44 per cent). This is consistent with the gender breakdown on incidence of childhood cancer (55 per cent boys and 45 per cent girls – Cancer Research UK, 2003). Most parents (82 per cent) were married or living as married, lone parents (single, separated or divorced, or widowed) accounted for less that 20 percent of respondents. Also, most parents (85 per cent) had more than one child and therefore had siblings to care for as well as their sick child. Almost all respondents were white (97 per cent), with two parents of mixed ethnic origin and one parent each of Arab, Argentinian, Black Caribbean, Chinese, Greek, Indian and Muslim (Yemeni) origin.

Table 4.4 gives details of the social class background of the sample compared with national figures. The pattern is similar and some differences are likely to be due to the different age composition of this sample. However, unemployment is notably higher: 34 per cent of respondents and 17 per cent of their partners were unemployed. Answers to questions on effects of having a child with cancer on employment provide some indication of why this is so. Thirty-two per cent (n=97) of respondents indicated that they had to leave work to care for the child and 17 per cent (n=52) had not been able to return to work. Nine per cent (n=22) indicated that their partner had to leave work to care for the child and seven per cent (n=18) had not been able to return to work. In addition, 21 per cent (n=64) of respondents and 22 per cent (n=53) of partners had to reduce their hours at work. Fourteen per cent (n=29) of respondents indicated that their employer had not been supportive and for 17 per cent (n=29), this was the case for their partners.

Table 4.4 Socio-economic classification of respondents and partners (National Statistics Socio-Economic Classification (NS-SEC)

Class	*Label*	*Percentage of people aged 16-74 (England & Wales)[1]*	*Percentage of respondents (n=303)*	*Percentage of partners of respondents (n=246)*
1	Managerial & professional occupations	27	31	40
2	Intermediate occupations	9	13	4
3	Small employers & own account workers	7	4	11
4	Lower supervisory & technical occupations	7	3	11
5	Semi-routine & routine occupations	21	8	11
Unemployed		4	34	17
Not classifiable for other reasons[2]		25	7	5

[1] National Statistics Socio-economic Classification: Table KS14a http://www.statistics.gov.uk/downloads/census2001/ks_ua_ew_part2.pdf

[2] 'Not classifiable for other reasons' includes full time students and people whose occupation has not been coded.

With regard to the type of childhood cancer, leukaemia was the most common cancer type (45 per cent) and then brain tumours (12 per cent). For each of the other types of cancer reported, all accounted for seven per cent or less of the achieved sample, see table 4.5.

Table 4.5 Type of childhood cancer

Type of Cancer	*Parents with children with this type of cancer (n=294)*
Leukaemia	45 %
Brain tumours	12 %
Neuroblastoma	7 %
Wilm's tumour	6 %
Hodgkin's lymphoma	6 %
Non-Hodgkin's lymphoma	5 %
Rhabdomyosarcoma	4 %
Ewing's sarcoma	4 %
Other	3 %
Retinoblastoma	2 %
Osteosarcoma	2 %
Germ cell tumours	1 %
Langerhaus cell histiocytosis	1 %
Liver tumours	1 %

Fifty-six per cent of responses (n=170) were from parents of children off treatment and 44 per cent (n=133) from parents of children on treatment. The off treatment group included 16 children (five per cent) who had finished treatment for more than five years and hence qualified as 'survivors'. However, given the small size of this group, it was not analysed separately, but added to the post treatment group to form a general off treatment group.

Just over half the children received treatment at one centre (56 per cent, n=168), with 44 per cent (n=133) experiencing shared care, where treatment was shared between two or more hospitals. The pattern of treatment most typically comprised frequent hospital stays and/or one or more hospital stays of more than two weeks (41 per cent, n=118), or a long stay in hospital after diagnosis followed by treatment mainly as an outpatient (31 per cent, n=89). Patients were least likely to have been mainly treated as an outpatient (21 per cent, n=60) or to have had just one or two nights stay in hospital (eight per cent, n=22).

4.2.2 Facilities and practical issues for families (Section B)

This section looked at parents' experiences of facilities for families and other practical concerns in relation to when their child was staying in or attending hospital. This included questions on accommodation facilities for parents and other family members; general facilities for inpatients and outpatients; teenage facilities for inpatients and outpatients; and practical support services for families, such as transport services and help completing welfare benefit claim forms.

Family accommodation

For accommodation facilities for parents and other family members, the only key area of unmet need concerned hospital catering. Perhaps unsurprisingly, most parents (88 per cent) would have found it helpful if free food had been provided for them when staying in hospital. Other than this, there were no key areas of unmet need, but also absent were high levels of satisfaction with family accommodation facilities.

General facilities for inpatients and outpatients

Hospital catering was also identified as a key area of unmet need for inpatients by those on treatment (41 per cent), with the proportion being significantly higher than for those off treatment (28 per cent) ($\chi^2 = 5.12$, df = 1, $p<0.05$).

Another high area of unmet need (37 per cent) for inpatients was the provision of age appropriate activities, such as magic shows and quiz nights.

With regard to high levels of satisfaction with general facilities, the provision of television and video/DVD players for inpatients were areas where satisfaction was reported as high (83 per cent and 75 per cent respectively). Similarly, provision of playroom facilities for inpatients was an area of high satisfaction for parents of the youngest two age groups for whom playrooms are most relevant (0-5 Years – 80 per cent; 6-11 years – 83 per cent), and 71 per cent of parents of the youngest children were satisfied with playrooms for outpatients, with 65 per cent of parents of 6-11 year olds being satisfied with this. This again stresses the importance of, and parents' appreciation of, activities to occupy children and young people in hospital.

Teenage facilities for inpatients and outpatients

The analysis of teenage facilities for inpatients was confined to responses from parents whose children were on treatment rather than those off treatment, in order to accurately reflect current inpatient facilities for teenagers in light of recently opened teenage cancer units. Key areas of unmet need were wide ranging when examining facilities for both teenage inpatients and outpatients. However, there were significant differences between those whose sons and daughters were treated at centres with and without separate teenage units. A number of areas of unmet need were found only amongst those treated at centres without teenage units. For inpatients, key areas of unmet need at centres without teenage units were for separate accommodation (64 per cent), kitchen facilities (82 per cent) and teenage activities. For outpatients, a teenage lounge (42 per cent), kitchen facilities (42 per cent), teenage activities (53 per cent) and activity coordinators (50 per cent) were key areas. A teenage lounge for inpatients was a key area of unmet need (55 per cent) in centres without teenage units, but also a high area of unmet need (37 per cent) in centres with teenage units, as was a teenage activity room (64 per cent and 37 per cent respectively).

In both centres with and without a separate teenage unit, there were no high levels of satisfaction found in relation to facilities for teenagers.

Other practical issues for families

Car parking issues are a major source of dissatisfaction for families. Facilities to park at hospital are a key area of unmet need for parents, with 70 per cent reporting unsatisfactory or non-existent provision. For those on treatment, help with parking costs was a key area of unmet need (40 per cent) with the proportion being significantly higher than for those off treatment (26 per cent) ($\chi^2 = 6.65$, df = 1, $p<0.01$).

No other key areas of unmet need were identified in relation to financial information, advice and support; transport services; holiday services; and patient co-ordinators to deal with practical problems for families. However, parents of teenagers were more likely than parents of younger children to identify someone to give them a break from looking after their son or daughter whilst in hospital as a high area of unmet need and less likely to be satisfied with support provided in this area (37 per cent) ($\chi^2 = 21.4$, df = 6, $p<0.01$).

With regard to language support workers for parents whose first language is not English, the low response rate from ethnic minority families has already been noted. This accounts for 96 per cent of the sample not needing interpreter or translation services. However amongst those for whom these services were required (n=10), unmet need was high at 50 per cent.

Once again, high levels of satisfaction with any of the other practical issues for families addressed in the questionnaire were absent.

4.2.3 Care issues for families (Section C)

In this section data were collected on parents' involvement in their children's care and treatment and on parents' experiences of continuity of care and shared care.

No key areas of unmet need were found. Parents reported high levels of satisfaction with the extent to which staff relied on them to care for their child (82 per cent) and the extent to which they acted as their child's treatment co-ordinator (84 per cent). They also reported high levels of satisfaction (85 per cent) with both their own and their child's involvement in decision making regarding treatment and care plans. Additionally high levels of parent satisfaction (79 per cent) were found with regard to the extent to which children received continuity of care.

Data on parents' satisfaction with communication between the main treatment centre and the shared care hospital, and the availability of professional expertise in the shared care hospital, were less conclusive. Neither high levels of satisfaction nor high unmet need were found.

4.2.4 Social and emotional support (Section D)

In this section parents' experiences of social and emotional support services in preparation for admission, in hospital and at home were explored. Parents were asked about the support they received from different professionals as well as from 'befrienders' and other parents with children with cancer or leukaemia. If parents found contact with other parents helpful, they were asked to indicate their preferences for making this contact. The section concluded with an examination of complementary therapies, informal leisure activities or events organised by hospital and other staff, and spiritual support.

A counselling service for parents was identified as a key area of unmet need (41 per cent) across all groups. Also, for parents of older children, couples counselling was a key area of unmet need (44 per cent), with the proportion identifying this being significantly higher than for parents with younger children ($\chi^2 = 6.01$, df = 2, $p<0.05$).

Key areas of unmet need across all groups were also found for emotional support from a 'befriender' providing informal support through phone calls and hospital or home visits (45 per cent), and for support from a professional key worker providing emotional support, and co-ordinating and liaising with services (42 per cent).

Whilst support with children's behaviour and emotional problems was not found to be a key area of unmet need amongst the total sample, amongst those who report needing this type of psychological support (n=201), 46 per cent were dissatisfied with provision or received no provision.

Support from other parents was not a key area of unmet need. However amongst those who found contact with other parents helpful, almost half wanted to make this contact through a telephone network and, of these, most were prepared to provide this telephone support themselves. See Table 4.6 for details of parents' preferences for making contact with other parents. (Please note that parents could indicate more than one preference).

Table 4.6 Parents preferences for making contact with other parents

Type of contact	*Parent respondents preferring this type of contact (n=249)*
By a phone network of parents	46%
➢ Parents prepared to provide phone support for others (n=111)	➢ 89%
On a one-to-one basis	45%
At a parent support group in hospital	40%
At a parent support group in the local community	39%
At an informal weekly drop-in session in clinic	28%
At an informal weekly drop-in session on the ward	23%

Complementary therapies, including aromatherapy, reflexology and homeopathy, were not needed by more than half the parents, although around a third of parents reported unmet need for some type of complementary therapy.

In relation to satisfaction with social and emotional support services, parents reported a high level of satisfaction with support received from nurses or social workers in hospital (71 per cent).

4.2.5 Support for other family members (Section E)

This section collected data on the support provided to siblings and grandparents. Questions explored if siblings and grandparents were supported through having someone to talk to about their concerns, either at home or in hospital, and through sharing their experiences in support groups based at the hospital or in their local community. Also examined were activity days and school visits for siblings, and the provision of information and medical training for grandparents.

In relation to sibling support, no key areas of unmet need were found overall. However, for all the sibling issues addressed, significantly higher levels of unmet need were found amongst the siblings of children in the older age groups.

Someone to talk to brothers or sisters at home and in hospital was a key area of unmet need for the 12-19 years group (53 per cent for at home and 48 per cent for in hospital), with parents of 6-11 year olds off treatment also reporting a high level of unmet need (34 per cent and 39 per cent) for this support. A hospital-based sibling support group was another key area of unmet need (42 per cent) for the 12-19 years group.

Someone to visit a siblings’ school to explain their brother or sister’s illness and treatment and to answer questions, was a key area of unmet need in the 12-19 years group.

The relationship between age of the child with cancer and needs for sibling support is likely to be because older child patients are more likely to have siblings in the older age groups, for whom parents perceive a greater need for information and support around their brother or sister's illness.

Parents did not report high levels of satisfaction with support services for siblings. Indeed satisfaction was low at no more than 15 per cent for any of the different ways of supporting siblings included in the questionnaire.

For grandparents, information about their grandchild’s illness and treatment was identified as a key area of unmet need (48 per cent) across all groups. Someone to talk to grandparents was also a high area of unmet need (36 per cent).

As for siblings, there were no high levels of satisfaction with support services for grandparents. For all the types of support addressed, parent satisfaction was no more than ten per cent.

4.2.6 Returning home after treatment (Section F)

Parents whose children had returned home after treatment were asked to complete this section about home-based support from both hospital staff and community professionals. This included parents’ preferences for out-of-hours community nursing support and for the type of support they would like their GP to provide. It also looked at the provision of medical training, equipment and supplies to enable parents to care for their child at home; practical equipment for the home such as wheelchairs and bath aids; and support with childcare and domestic responsibilities.

The only key area of unmet need (43 per cent) found overall amongst parents was for support from an end of treatment meeting with a group of parents and staff, such as a nurse and social worker. This was highest (49.4 per cent) for the off treatment group ($\chi^2 = 7.22$, df = 1, $p<0.01$). In addition, key areas and high levels of unmet need were found amongst particular age and treatment groups for different types of support.

Within the off treatment group, but not the on treatment group, there was a high area of unmet need (39 per cent) for proactive phone calls from hospital staff to check on progress ($\chi^2 = 8.28$, df = 1, $p<0.05$).

Over half the respondents reported not needing help with childcare and domestic responsibilities. However among parents who reported a need for childcare and domestic support (n=120), this need was not met for 68 per cent. Also, 57 per cent of parents indicated they would use a free or subsidised agency cleaning service if it was provided for when they returned home with their child after treatment.

Support from their GP was a high area of unmet need for parents of the two younger age groups (36 per cent and 37 per cent). The types of support they would like their GP to provide, are listed in Table 4.7 below. (Please note that parents could indicate more than one type of support).

Table 4.7 Type of support parents would like from their GP

Type of support	*Percentage of parents indicating a preference for this type of support (n=221)*
Be available for assessment and advice when child is ill at home	75%
Counselling support	42%
Advice on the normal developments of childhood (e.g. teething)	37%
Information about sources of financial help	21%
Diagnosis and knowledge of illness	2.5%
Phone call or home visit to check on family's welfare	2.5%
Prescriptions for drugs and medical supplies	1.5%
Easy/instant access	1.5%
General support and understanding	1.5%
General medical check up	0.5%
Supply of practical equipment	0.5%
Links to other support services (e.g. psychiatrist)	0.5%
Liaison between GP and treatment provider	0.5%

High levels of satisfaction were reported in relation to instructions from the hospital about who to contact and when if parents are concerned about their child, and being able to phone hospital staff for advice. Also, where parents reported a need for medical equipment and supplies at home (n=235), 81 per cent of parents were satisfied with this provision.

4.2.7 Education (Section G)

Parents whose children had started school completed this section on the education support provided for their child whilst staying in hospital and when returning to their home school. It explored staffing provision in hospital and at school; information for children and young people and for their classmates; liaison between hospital and the child’s school; and practical issues such as free school transport and support with arrangements for taking public exams.

For both primary and secondary school parents, written and video information for their child about returning to school and for their child’s classmates about the illness and treatment, were key areas of unmet need (54 per cent and 58 per cent respectively). Similarly, for all parents, an education co-ordinator to oversee the child’s return to school and liaise with service providers, was also a key area of unmet need (46 per cent). In addition, amongst parents who reported a need for free school transport (n=41) unmet need was high at 51 per cent.

Parents of primary school children reported a high level of unmet need (37 per cent) for the provision of classroom learning support assistants. This was significantly higher than for parents of young people of secondary school age ($\chi^2 = 10.72$, df = 2, $p<0.01$).

Overall, no high levels of satisfaction were found for the educational support services investigated in the parents survey.

4.2.8 Information and advice

This section explored parents’ experiences of both the different ways information was delivered to them and to their children, and the different types of information provided at different stages of the illness and after treatment. The different ways information was delivered included looking at written, audio, video and internet information, as well as information provided through play activities. The different types of information provided included looking at medical information before, during and after treatment, and practical information about parking, sources of financial help and specialist support groups.

Unmet need for information and advice services was widespread within families in relation to both different formats and different types of information.

For all the family, a key area of unmet need found overall was for video information about the illness and treatment (58 per cent for children, 50 per cent for siblings and 44 per cent for parents). This was significantly higher for children aged 6-11 and 12-19 and their siblings ($\chi^2 = 12.99$, df = 2, $p<0.01$ and $\chi^2 = 20.12$, df = 2, $p<0.001$).

For children and young people with cancer or leukaemia, a key area found overall was for an age appropriate hospital welcome pack (48 per cent). Parents of 0-5 year olds were more likely to say that this was not needed (49 per cent); but even in this group 37 per cent identified an unmet need, compared with 54 per cent in the 6-11 group and 51 per cent in the 12-19 group ($\chi^2 = 6.14$, df = 2, $p<0.05$). For siblings, written age-appropriate information about their brother’s or sister’s illness and treatment was a key area of unmet need for siblings of children in the oldest age group (60 per cent) but not for other age groups ($\chi^2 = 29.00$, df = 2, $p<0.001$). Written age-appropriate information was also a key unmet need for children and young people themselves in the 6-11 and 12-19 years age groups (42 per cent and 40 per cent respectively) but parents of the youngest age group were more likely to say that this was not needed ($\chi^2 = 51.50$, df = 6, $p<0.001$). Audio information was identified as a key unmet need only for the oldest age group (42 per cent) ($\chi^2 = 21.49$, df = 2, $p<0.001$).

For parents, key areas of unmet need found overall were for summary sheets of what was said at outpatient clinic appointments (59 per cent) and of their children's case notes (62 per cent). In addition, unmet need for an up-to-date record of their child's medication and treatment was high (35 per cent). Parents wanted this information not just for themselves but to inform others about their child's illness and treatment, especially the different professionals involved in their care. Forty-eight per cent of parents identified an unmet need for a hospital library facility to borrow cancer-related books and magazines.

Parents also wanted advice on, and assistance with, accessing information available on the internet. Key areas of unmet need were for a list of recommended cancer or leukaemia websites (52 per cent), and for an internet search service for parents without computer skills (41 per cent). Access to the internet in hospital was not a key unmet need for parents overall but only for parents whose children were on treatment (43 per cent) ($\chi^2 = 3.14$, df=1, $p<0.05$). However, amongst those who reported a need for online facilities at hospital (n=140), unmet need was high at 79 per cent. Similarly, audio information for parents and was a high area of unmet need (37 per cent) amongst the off treatment group ($\chi^2 = 3.50$, df = 1, $p<0.05$). Amongst parents who need written information in different languages (n=19), 74 per cent reported unmet need.

A final key area of unmet need (43 per cent) found for parents overall was for information about specific support groups for their child's diagnosis, such as the Neuroblastoma Society.

On a positive note, parents reported high levels of satisfaction (ranging between 70 per cent and 81 per cent) with the medical information they received from doctors or nurses before, during and at the end of treatment.

4.2.9 Body issues

This section explored parents' experiences of the support provided to help their children deal with body changes resulting from treatment. Where a child's treatment could have affected their fertility, parents were also asked about how this was dealt with in relation to whether fertility was discussed and whether it was dealt with sensitively, and to the information and support provided to parents and young people.

No key areas of unmet need or high levels of satisfaction were found in relation to support provided to help children and young people deal with weight gain and loss, effects of surgery such as scarring or fatigue and hair loss following treatment. However, amongst those who reported a need for support to help their child deal with amputation (n=16), 50 per cent reported an unmet need.

For parents whose children’s fertility may have been affected by cancer treatment (n=252), 72 per cent reported that fertility matters were discussed either at the start of treatment or at another time. For 28 per cent of parents, therefore, fertility issues were not discussed despite their relevance. For 87 per cent of parents, their children were not given the option of talking to someone of their own gender. The older age group (12-19) were most likely to have had this opportunity ($\chi^2 = 12.65$, df = 2, $p<0.01$), but even in this group only 23 per cent had been given this option. For parents whose children had not had this option, 35 per cent felt that this would have been helpful, with these being predominantly parents of the older age group (60 per cent compared with six per cent of parents of 0-5s and 17 per cent of parents of 6-11s: $\chi^2 = 24.24$, df = 2, $p<0.001$). Indeed for those whose child took up the option of talking to someone of their own gender (n=11), 91 per cent thought that this was helpful for their child. Additionally 45 per cent of parents reported that insufficient support was provided for them around fertility issues and 44 per cent that insufficient support was provided for their children. In both cases, parents with children in the youngest and oldest age groups reported significantly higher levels of unmet need ($\chi^2 = 10.90$, df = 2, $p<0.01$ and $\chi^2 = 7.56$, df = 2, $p<0.05$). Similarly, parents of the youngest and oldest age groups reported high levels of unmet need for information about fertility at diagnosis (38 per cent and 42 per cent compared with 20 per cent for the 6-11 group: $\chi^2 = 6.08$, df = 2, $p<0.05$). Nevertheless, overall parents reported a high level of satisfaction (85 per cent) with the sensitivity with which fertility issues were managed.

4.3 Results of the children and young people's questionnaire survey

The children and young people’s questionnaire (see Appendix 10) was completed by 112 children and young people between the ages of ten and 19 years. The questionnaire was divided into 12 broad sections, the results of each section are reported below. The questionnaire explored if children and young people had received a range of psychosocial services or support and asked them to indicate if they had found these services helpful or unhelpful. In contrast to the parents’ questionnaire, which employed a satisfaction scale (one to five), children and young people, were asked to evaluate their satisfaction in terms of ‘happiness’, ‘unhappiness’ or ‘it’s not important to me’. However, in terms of analysis, data were analysed and are reported in a similar manner to the parents’ questionnaire, hence, the same definition of unmet need is employed with key areas of unmet need defined as 40 per cent or over reporting the need as not met, and high levels of unmet need (over 35 per cent) reported when they follow the wider pattern of unmet need. Once again, areas of unmet need generally refer to the overall sample or to a sub-group, i.e. a specific age group or those on or off treatment, when this sub-group shows a key or high level of unmet need which is significantly different from the rest of the sample. In terms of satisfaction, 70 per cent is used as the baseline to indicate areas children and young people regard as providing high levels of satisfaction. A complete set of tables documenting levels of unmet need and satisfaction can be found in Appendix 11. On questions asking for a rating of whether a service had been helpful or not, it is important to note that some respondents indicated that they received or did not receive a service, but did not provide an assessment of its helpfulness/ unhelpfulness or potential helpfulness/potential unhelpfulness as requested by the questionnaire. In order to present reliable figures on unmet need and satisfaction, these responses are not included and unmet need for these types of questions is defined as numbers indicating that they did not receive a service and it would have been helpful and satisfaction is defined as numbers receiving a service and rating it as helpful.

4.3.1 Personal details (Section A)

The first section of the questionnaire collected personal details about the child/young person and their illness and treatment. As noted above, 112 children and young people completed the questionnaire, within this, 33 per cent (n=37) of respondents were 10 to 12 years and 67 per cent (n=75) were 13 to 19 years. In a similar manner to the parents’ questionnaire, there were more males (62.5 per cent, n=70) than females (37.5 per cent, n=42). The categorisation of age used in this analysis (10-12 and 13-19 years) is slightly different to that employed by the parents’ questionnaire, as it was felt that 13 years is often viewed as the onset of the teenage years in terms of facilities and support provision. Hence, young people’s experiences and expectations of services may begin to alter at 13 years. For brevity, in the following text the term 'children' is used to refer to refer to the 10 to 12 years old group and 'young people' refers to the 13 to 19 years old group.

Seventy-nine per cent (n=88) of children and young people lived with both parents; 20 per cent (n=22) with a single parent, which in all cases was their mother, and one child lived with a guardian. Eighty-eight per cent (n=98) of children lived with one or more siblings. In terms of ethnicity, the sample was predominately white (95 per cent, n=106). Two respondents were Asian or Asian British, one respondent was Chinese and three children and young people described themselves as of mixed or other ethnicity. This lack of ethnic diversity must be acknowledged, however, the project did not seek to compare the psychosocial experiences and support needs of different ethnic groups, this deserves specific research in its own right.

Following a similar pattern to the parental sample, amongst children and young people completing the questionnaire, leukaemia was the most frequently experienced type of cancer (42 per cent, n=47). Brain tumours and Hodgkin's Lymphomas were each diagnosed for 12.5 per cent (n=14) and Non-Hodgkin's Lymphoma for eight per cent (n=9) of the sample. The remaining 25 per cent of the sample were diagnosed with a wide range of cancers, as described in Table 4.8.

Table 4.8 Type of cancer

Type of Cancer	*Per cent of children and young people with this type of cancer (n=108)*
Leukaemia	42
Brain tumours	12.5
Hodgkin's lymphoma	12.5
Non-Hodgkin's lymphoma	8
Rhabdomyosarcoma	6.3
Ewing's sarcoma	4.5
Osteosarcoma	2.7
Germ cell tumours	2.7
Wilm's tumour	0.9
Liver tumours	0.9
Neuroblastoma	0
Langerhaus cell histiocytosis	0
Retinoblastoma	0
Other	2.7

Amongst the sample of children and young people, nearly three-quarters (71 per cent, n=69) of the sample's in-patient experiences were either a long or a number of long stays in hospital. Staying one or two nights was the most frequent pattern of treatment for only nine per cent of the sample. However, it is also important to note that 20 per cent (n=22) received treatment mainly as an out -patient. As with parent responses, there were more children and young people off treatment (70 per cent, n=78) compared to those on active treatment (30 per cent, n=34). Amongst those off treatment, 57 per cent (n=64) had completed treatment within the last five years and 13 per cent (14) were regarded as long-term survivors (i.e. had completed their treatment over five years ago). A separate analysis of survivors was not conducted due the small sample size. Furthermore, analysis by specific sub-groups, such as children on treatment/children off treatment, young people on treatment/young people off treatment was particularly problematic for some sub-groups due to small numbers. For example, although 34 children and young people were on active treatment, only 10 fell into the 10 to12 year age range compared to 24 in the 13 to19 age range.

4.3.2 Staying in hospital (Section B)

This section explored the experiences of children and young people whilst staying in hospital. As in-patients, children and young people were asked if they had needed and received a range of facilities and then to rate whether this was helpful or would have been helpful if provided. The list of facilities encompassed different forms of personal accommodation, such as a bed on a children's ward or a teenage ward, accommodation and facilities for family members, for example a bed for Mum and Dad, general facilities, such as bathrooms and visiting hours and finally, a variety of leisure activities and spaces.

In terms of personal accommodation, children and young people noted high levels of satisfaction with regard to the provision of bathrooms (84 per cent) and visiting hours, for both close family members (94 per cent) and extended kin and friends (89 per cent). Three additional areas of good provision were highly valued by a large proportion of the sample. The first highlights the importance of accommodation for parents, 69 per cent of children and young people found the provision of a bed for their parents helpful. The latter two areas relate to retaining or creating one's own personal space whilst in hospital: 70 per cent of respondents valued having a bed with some privacy and 68 per cent had been allocated space for personal belongings.

Amongst children and young people, levels of satisfaction with leisure facilities and activities varied. However, there were three key areas of satisfaction in terms of activities provided: televisions (91 per cent), videos and DVDs (82 per cent) and play stations and games (77 per cent). In contrast, dissatisfaction was expressed amongst children and young people across the illness trajectory (on and off treatment) in terms of the appropriateness of available toys and activities (47 per cent).

Similarly to parents' views, dissatisfaction was most frequently highlighted in relation to unappetising hospital food (66 per cent).

4.3.3 Visiting hospital (Section C)

Section C focused upon the experiences of children and young people visiting hospital as outpatients. Following a similar format to the previous section, children and young people were asked to evaluate the provision of a range of facilities available to them. Once again, general facilities, such as lounges, playrooms, snack making amenities and a selection of leisure activities were examined.

In contrast to inpatient experiences, levels of satisfaction with facility provision were generally lower amongst outpatients. In fact, there was a marked absence of key areas of satisfaction. Leisure provision in terms of televisions, play stations and games, once again appeared to be areas of good provision, however, in terms of satisfaction they did not emerge as key areas.

Areas of unmet need followed a similar pattern to inpatient experiences. Hence, children and young people highlighted the provision of age appropriate toys and activities as a key area of unmet need (60 per cent). When asked whether more toys and activities were needed for children and/or teenagers, the majority replied teenagers for both inpatients (79 per cent) and outpatients (92 per cent).

4.3.4 Information and advice (Sections D and E)

Section D explored both the type of information that children and young people had received and how they had received it. For example, different information formats, such as books, audiovisual and the internet, and the approach medical staff had taken, were evaluated. Co-ordinating information amongst shared care centres was also examined. Section E focused upon financial issues, specifically advice and help for young people claiming state benefits and was thus relevant to only those 16 years and over who could claim benefits in their own right.

In general, there was considerable satisfaction amongst children and young people with regard to information. Three key areas emerged from the data. In terms of making information as accessible as possible, the vast majority (88 per cent) of children and young people indicated that staff used easily understandable words and 78 per cent also felt and valued the fact that doctors spoke directly to them rather than via their parents. As previously noted, information needs and preferences differ over the illness trajectory; however, respondents (75 per cent) were generally satisfied with the information they had initially received when finding out about their illness.

Areas of unmet need tended to focus upon provision of different types of information, Forty two per cent of respondents would have welcomed more video information about cancer. Children and young people across the illness trajectory mirrored parents' experiences, as a substantial number (35 per cent) wanted more help finding information on the internet.

Information sharing amongst shared care centres did not emerge as an area of either high satisfaction or high unmet need, however, there was generally more satisfaction than dissatisfaction. Similarly, young people’s experiences and evaluations of help and advice on financial benefits did not highlight specific areas of satisfaction or key or even high areas of unmet need. However, it is important but unsurprising to note that when help was provided, 84 per cent of young people received this help from social workers.

4.3.5 People who help and support me (Section F)

Within this section, the help and support of family, friends and professionals was explored. Children and young people were invited to evaluate close family support whilst in hospital, the importance of talking to different types of peers and the role played by different types of professionals and how they offer support.

The questionnaire highlighted that over 90 per cent of children and young people felt it was important for close relatives, such as Mum and Dad, to be able to stay with them whilst in hospital (96 per cent) and also to help care for them (97 per cent). Indeed, over 80 per cent of respondents indicated that this family support was ‘very’ important to them. The relevance of centres providing opportunities for parents to stay and care is thus emphasised. Similarly, both children and young people also noted the value of talking to peers. Over 70 per cent of the sample felt that it was important to talk to school friends (78 per cent) or other children in hospital with cancer (71 per cent) during their illness. Hospital staff can play an influential role facilitating opportunities for children and young people to meet and talk to other children with cancer. However, the survey revealed that this was a key area of unmet need, as 42 per cent of respondents wanted more help with this from hospital staff.

Support from hospital staff was also generally welcomed and valued. In fact, the support doctors and nurses provided emerged as a key area of satisfaction with regard to children and young people feeling that they made time to talk to them (85 per cent) and also they actually listened to their wishes and feelings (73 per cent). A slightly lower number (66 per cent) felt that staff acted on their wishes and feelings.

Over half of the sample (62 per cent) had talked to a social worker; however, it is also important to note that amongst those who had not talked to a social worker (n=29 or 27 per cent of the sample), the vast majority (88 per cent, n=22) did not wish to, so this was not specifically an area of unmet need. Amongst the young people who had talked to a social worker, there was generally a great deal of satisfaction. For example, 77 per cent felt that their social worker listened to them. A substantial number of respondents indicated that social workers did not merely listen to them but also acted on their wishes and feelings (68 per cent) and provided practical help (67 per cent). For these children and young people, social workers were clearly an important source of psychosocial support.

With regard to counselling, in contrast to the parents’ questionnaire, an opportunity to talk to a counsellor or psychologist did not emerge as a key area of unmet need, however, it was also not a key area of satisfaction.

4.3.6 Other forms of help and support (Section G)

Section G explored other forms of psychosocial help and support offered to children and young people. For example, support groups and their different formats, holiday provision and alternative therapies, such as aromatherapy, massage, and art and music therapy.

Less than a fifth of the sample (17 per cent, n=18) had attended a group(s) for children or young people with cancer. However, amongst those who had not, the vast majority (73 per cent) did not wish to attend any groups. An opportunity to attend groups was thus not viewed as an important unmet need by respondents. It is also interesting to note that amongst those who had not attended a group(s) but wished to do so (27 per cent), this was significantly higher amongst those on (52 per cent) rather than off treatment (16 per cent) ($\chi^2 = 11.98$, df = 1, $p<0.001$). For those currently facing treatment, the need or desire for support or company of others may be more pronounced, especially if one is staying for long periods in hospital.

For those attending support groups, although only a small proportion of the overall sample, almost all (n=17/18) of these respondents were happy with the support received. When asked how they liked groups to be organised, the two key criteria were activity based meetings (72 per cent) and groups for different ages (61 per cent). The importance of activities was similarly reiterated by those who had not attended any groups but would like to do so. Once again, although a small proportion of the general sample, 78 per cent (n=18) wanted activity-based meetings.

Neither holidays nor the provision of alternative therapies emerged as key areas of satisfaction or dissatisfaction amongst survey respondents.

4.3.7 Preparation for treatment (Section H)

This section focused upon the preparation for treatment provided before and during treatment by hospital staff. Areas covered included methods used, opportunities to make choices, and advice and explanations.

This was generally an area within which children and young people expressed a great deal of satisfaction, hospital staff were viewed as both supportive and informative. The key areas of satisfaction were: 86 per cent of respondents felt that hospital staff, such as doctors and nurses, spent enough time explaining their treatment to them and 86 per cent also felt they explained possible side effects that may occur. Eighty per cent felt that staff provided helpful advice that made or sought to make treatment more bearable. Although falling just below key status, a substantial proportion of the sample (67 per cent) welcomed and was satisfied with the choice making opportunities staff provided. In contrast, the use of toys or books to aid understanding emerged, as a significantly high area of unmet need amongst specific subsections of the sample (χ^2 = 8.29, df = 2, $p<0.05$), notably children on treatment (60 per cent) and young people off treatment (37 per cent), who may of course have fallen into the younger age group when on treatment.

4.3.8 Returning home after treatment (Section I)

Support provided on return home by hospital staff and community professionals/ practitioners was explored in this section. Children and young people were asked about hospital staff support received in relation to issues such as medication, equipment, independence and coping with family relationship changes. The availability of community support from GPs, nurses and physiotherapists was also explored.

The survey highlighted that children and young people were generally satisfied with the support they received from hospital staff on return home. Four key areas of satisfaction emerged, with independence issues and opportunities important themes within three of these areas. For example, 75 per cent felt that hospital staff had explained how to look after equipment, such as their ‘line’, 71 per cent had been shown how to take their medicine and 75 per cent indicated that they had been helped to become as independent as they wanted to be. Seventy-nine per cent indicated that their parents had received support with regard to looking after equipment.

However, there was one pocket of high unmet need: children were significantly more likely than teenagers to highlight unmet need for hospital staff to talk to them about being at home (37 per cent compared to 13 per cent) (χ^2 = 8.08, df = 2, $p<0.05$).

In contrast, there were no key areas of satisfaction or unmet need with regard to hospital staff helping children and young people cope with parent or sibling relationship changes.

4.3.9 Returning to school, college or work (Section J)

Section J examined the support provided by staff (school, college, work or hospital) both before and on return to school, college or work. Children and young people were asked to consider a range of educational, social and practical issues, such as opportunities to talk to staff, information provided both to respondents and to their peers, and ways that school, college or work had been understanding and accommodating to any side effects of cancer that they may have experienced. In addition, support provided by home tutors was also explored. Given the age profile of respondents, the results presented refer predominately to children and young people’s experiences of school and college rather than work.

In contrast to the results of the parents' survey, amongst children and young people there was an absence of key or high areas of unmet need. In fact, respondents were relatively satisfied with the support that had been offered to them before and on return to school or college. For example, on return, both children and young people across the illness trajectory indicated that they had received and were satisfied with both the educational and practical support provided. In particular, 73 per cent highlighted that that school and college staff had helped them to catch up with their studies and 74 per cent felt that school and college staff had been understanding about and accommodating towards issues of changed appearance, such as wearing a cap or bandanna in class. As one would expect, not all children and young people in the survey had experienced or needed the support of a home tutor, however, amongst those who had a home tutor, there was a great deal of satisfaction with the educational and practical support provided. In fact, all three issues explored in the questionnaire emerged as key areas of satisfaction: 78 per cent felt that their home tutor gave them enough time each week; 70 per cent that they understood about their cancer and its side effects; and 75 per cent felt that their tutor met their educational needs, as they understood the work that needed to be covered.

Support was also provided before returning to school, as over 83 per cent of respondents noted that their parents had been offered an opportunity to discuss returning issues with school/college staff and 79 per cent of children and young people had been given a chance to return on a gradual basis. However, although levels of satisfaction were high in these areas, 62 per cent and 63 per cent respectively, they fell just short of key satisfaction status.

4.3.10 Physical changes (Section K)

Children and young people were asked to consider a range of immediate and future physical changes that they may encounter during the course of their illness. Hair loss was initially addressed, exploring if and when discussion had taken place and the different options available. Other effects of treatment were also examined, such as weight loss/gain, effects of surgery and dealing with tiredness. Finally, the complex issue of fertility was raised. Respondents were asked if fertility issues, such as possible side effects and preservation, had been discussed, when and by whom.

Amongst the sample of children and young people, 94 per cent had experienced hair loss during the course of their treatment. Despite this, discussion of hair loss did not emerge as a key or high area of unmet need or alternatively, an area of key satisfaction. Over 70 per cent of respondents indicated that staff had discussed hair loss prior to (81 per cent) and during (71 per cent) treatment and had also explained a range of options available to them, such as shaving one's head, wearing a wig or a bandanna. However, specific expressions that this was 'helpful' fell below 55 per cent in all three areas. In terms of other side effects, areas of key satisfaction and unmet need were similarly absent.

Under half of the sample (41 per cent, n=44) noted that staff had discussed fertility issues with them and the same proportion indicated that they had not experienced staff discussion. Thus, it is interesting to note that nearly a fifth of the sample (19 per cent) were unsure if discussion had taken place or not. Although the fertility questions were answered by just under half of the sample (n=43 to 45), responses did not highlight any key areas of satisfaction or unmet need. It is interesting to note that whilst only 28 per cent had the opportunity to discuss fertility with someone of their own gender, the young people, unlike their parents, did not see this as an area of unmet need: only three of the 19 not experiencing it thought it would have been helpful.

However, it is important to note that amongst those who had not discussed fertility issues at all (n=36), half (50 per cent) would have welcomed staff discussion.

4.3.11 The future (Section L)

The final section invited those who had finished their treatment five years ago or more (i.e. survivors) to consider the provision of and their need for ongoing services and support. Issues such as hospital check-ups and survivor support groups, their format and content were evaluated. The results however, must be viewed in context, as only 14 respondents (six children and eight young people) identified themselves as ‘survivors’ and completed section L. With such a small sub-sample, we cannot realistically explore general trends in satisfaction or unmet need.

All 14 survivors still had hospital check-ups and for the vast majority (n=13) these were attended at least annually. There was also a great deal of satisfaction with these check-ups (n=13). All respondents talked to doctors at check-ups and six also talked to nurses, whereas none of the survivors had spoken to a social worker. Discussion of survivorship issues and the future, such as explaining about your cancer to others and future career choices, did not raise either key areas of satisfaction or unmet need.

Thirteen of the 14 survivors had not attended a survivor support group. However, out of this 13, five children and young people would have welcomed the opportunity to attend a group. When asked how they would like a support group to be organised, all five highlighted a preference for activity-based meetings. This mirrors the wider sample’s general preference for activity based support group meetings.

Chapter 5. Discussion and Conclusions

This chapter draws together the results of the surveys of service provision and the family survey of parents and children/young people and places these in a wider policy context. The centre survey provides an overview of current psychosocial services and support that UK paediatric oncology treatment centres and their staff provide for children/young people with cancer and their families across the illness trajectory. The family survey complements these data, as it presents an alternative perspective, that is the services and support that parents and children/young people actually feel they have received and those that they feel they need. Presenting an overview of the results, areas of consensus amongst the centres and families, and areas of diverging opinion and practice, are highlighted. Parents and children's experiences and expectations of psychosocial support sometimes diverge; these differences will also be noted and discussed. Where appropriate, reference will also be made to voluntary sector survey and qualitative interview data. However, it must be recognised that this is more limited and specific data, as the voluntary sector survey only targeted key agencies and the qualitative sample of children/young people and parents was relatively small. The chapter concludes by summarising the study's key themes and messages.

5.1 Strengths and limitations of the study

As noted above, this study draws together service providers and service users' experiences of paediatric psychosocial support services. It moves beyond previous studies, as it provides a UK wide rather than regional analysis or one limited to a few centres. In addition, the views of children and young people were sought in an age appropriate manner and are considered separately to those of parents. Recognising the importance of these different views, the study is able to identify and discuss areas of agreement and disagreement between service providers and service users and highlight areas of service satisfaction and unmet need. In addition, comparisons can be made at three different levels, similarities amongst parents and children/ young people, differences between parents and children/young people, and the experiences and needs of parents and children/young people at different ages and stages of the illness trajectory.

Despite these strengths, it must be recognised that the study has certain limitations. Whilst the family survey response rate was respectable (54 per cent of parents completed a questionnaire), especially when one considers the sensitivity of the subject and the many demands that treatment and caring for a child with cancer places upon families, it would have been advantageous to achieve a response rate of over 60 per cent. However, as noted in Chapter 4, the sample of parents and children/young people achieved was generally representative of the total population the survey targeted in terms of age and treatment stage. When the sample of children and young people who responded was broken down in terms of age and stage of treatment (on and off treatment), the numbers were small in some categories and meant that some sub-sample analysis could not be carried out reliably. Similarly, it must be acknowledged that the sample of parents and children/young people was predominately white and included a very small number of long term survivors, which precluded specific analysis of ethnicity and survivorship issues.

5.2 Staffing

Amongst centres across the UK, no clear pattern emerged in terms of the number of staff involved in psychosocial support in each centre (whole time equivalent posts) in relation to the number of new patients the centre received each year. The staff ratios that do emerge do not appear to be associated to any clear or discernable factors, however, the degree of data centres provided varied and was frequently partial.

The area of poorest staff provision was counselling and psychological support; indeed, only one centre employed a counsellor on a regular basis. With regard to psychological support, only four centres employed a psychologist on more than a half time post and nine did not regularly employ a psychologist at all. Not all centres provided information about psychological staffing. This dearth of psychologists and psychological support was reiterated throughout the centre survey, as their involvement was noticeably absent in many areas of support and preparations. When asked to identify areas of potential concern and gaps, centre staff highlighted the dearth of psychologists and the need for more routine psychological input. This mirrors the shortage of psychologists found within the NHS - Department of Health figures show that over a quarter of clinical psychology posts are vacant (The Psychologist, 2003). The family survey provided important information about the effects of this shortage of psychologists and counsellors, as counselling was highlighted as a key area of unmet need by parents and support in dealing with children's behavioural or emotional problems was lacking for almost half of the families who needed this. Parents of both children and young people would welcome a counselling service for themselves and parents of young people felt that more relationship counselling for couples was needed. However, this stands in contrast to children and young people’s preferences, as counselling and psychological support was not identified as an area of key satisfaction or unmet need in the children’s survey. Indeed, a quarter felt they ‘didn’t need this’. The concept of counselling can be rather abstract and daunting and this may have coloured children’s perceptions.

The centre survey data continually highlighted the pivotal role that social workers play within centres. On one hand, it is encouraging to report that the vast majority of centres employed social workers as standard practice on a regular basis. However, the provision of social workers varied enormously, with the worst-case scenario being one social worker to 157 patients. In contrast to psychological staffing, where funding is largely statutory based, the important role the voluntary sector plays in social worker funding must be noted, in just over half of centres, social worker posts were solely voluntary sector funded. The survey points to the important role Sargent social workers play and many centres appeared to be very reliant upon their services. This is an important factor for future consideration in light of the recent organisational developments in Sargent and the corresponding changes staffing changes centres may experience. Some centre staff noted this in their comments and identified it as a potential future area of concern. The family survey similarly demonstrated the important but variable role social workers play within family support. Parents identified social worker and/or nurse support as a key area of satisfaction and for children and young people, although not all had talked to a social worker, amongst those who had their support was valued both practically and emotionally, especially being listened to. However, opinions seem to be polarised, for those who had not spoken to a social worker, there was not a desire to do so. Thus, opportunities to talk to and be supported by a social worker were not regarded as areas of unmet need.

Although occupying different roles within paediatric oncology teams, POONS and play specialists are clearly important members of the team. Indeed, the significant role that play specialists perform for children and their families whilst visiting or staying in hospital has been well documented (Woodgate, 2000; Van Dongen-Melman, 2000; Bearison, 1991). It is thus heartening to note that the employment of both play specialists and POONS was common practice amongst the vast majority of centres. However, as previously noted, staffing ratios varied, and play specialist centre trends did not always relate to the age of patients (i.e. those with the highest proportion of young children did not necessarily employ the most play specialists), provision appeared to be more *ad hoc*. Similarly, it is interesting to note that POONS and play specialist posts were largely state funded, although there was some joint funding, the voluntary sector generally played a rather more peripheral role.

5.3 Facilities and practical issues

5.3.1 Patient facilities

As one would expect, the centre survey indicated that it is common practice to provide access to more facilities, whether practical, social or educational, for inpatients compared to day and outpatients and this is mirrored by the family survey. Levels of satisfaction amongst parents and children/young people were generally higher for inpatients compared to outpatients. In some areas, such as leisure and education, day and outpatients can tap into inpatient facilities, but access varies across centres. Inevitably, centres have to prioritise and manage limited resources in favour of inpatients, however, the long hours that many day and outpatients face waiting for treatment and consultations need to be recognised and also catered for. In addition, the children's survey highlighted the importance of creating one's own personal space whilst staying in hospital. Amongst children and young people, the provision of a bed with some privacy and space for personal belongings were noted as key areas of satisfaction, opportunities to foster time for oneself are obviously valued.

The significance of age appropriate play and leisure facilities for children and young people, especially those facing extended stays, has been frequently demonstrated in past studies (Diefer-Hicks and Lavender, 2001; Woodgate, 1999; Bearison, 1991). It is thus positive to note that the provision of playrooms for inpatients was common practice amongst centres, as was the provision of televisions and telephones. However, it is not enough to merely provide a playroom, facilities such as this need to be accessible. It is thus disheartening to note in the centre survey that staff raised questions of accessibility, especially in terms of opening hours. Indeed, play resources were noted as an area of potential gaps and in need of development by a small number of staff. In the family survey, parents of children (0-12 years) were satisfied with play facilities and both parents and children/young people were satisfied with the provision of televisions and videos/DVDs. However, children and young people were dissatisfied with the provision of age appropriate toys and activities.

Computer provision similarly presented a complex picture. The centre survey suggested that computer facilities were standard provision for patients (especially inpatients) amongst centres and indeed, the children’s survey demonstrated that a substantial number of children and young people (65 per cent) were happy with the computers provided in hospital, particularly computer aided games and play stations (85 per cent). However, given the importance of computers in many children and young people’s everyday lives, it is rather surprising to note that only half of centres provide access to online information resources (internet information will be addressed in the information and advice section). Although not specifically examined, this may be due to a distinction that both centres and children/young people make between computer facilities for play/leisure and those for information.

At first glance, educational provision appears relatively consistent for inpatients, as centre survey data reported that the majority of centres provided a teaching area or classroom, and hospital teachers liaised with each child’s school. Indeed, over half had agreed educational policies. However, on closer analysis there was still a great deal of variation amongst centres in terms of policies and practice, as most centres did not have their policies formally recorded in writing. Despite this variation, the provision of educational facilities and school rooms did not emerge as a key area of satisfaction or dissatisfaction amongst parents and children/young people.

Within past literature, teenagers have highlighted the importance of age appropriate facilities and activities, especially those that foster a sense of maturity and encourage independence (Diefer-Hicks and Lavender, 2001; Woodgate, 1999; Bearison, 1991). It is thus welcome to see in the centre survey that it was common practice to provide some form of separate facilities for teenagers. However, patterns of provision varied amongst the centres and provision does not, of course, guarantee perceived appropriateness by teenagers themselves. Despite this, as one would expect, the centre survey indicated that teenagers appear to be best served at those centres with separate Teenage Cancer Trust (TCT) units. Although only five centres had a separate TCT unit, the number of these units is growing. At other centres, provision varied from separate teenager wards to partitioned areas on general children's wards. Patterns of provision are generally difficult to establish, however, it is unsurprising to note that those centres with lower levels of new teenage patients per year frequently had less facilities than those with higher levels. A distinction between centres with separate facilities similarly emerged in the family survey, as unmet need was higher in centres without separate teenage units. In these centres, key areas of dissatisfaction were identified for inpatients and outpatients, including separate accommodation, activity coordinators and kitchen facilities. However, provision in centres with separate units did not escape identification of unmet need, as dissatisfaction was found about teenage lounges and activities in both centres with and without separate units. It is also important to note the absence of any key areas of satisfaction identified by parents with regard to teenage facilities.

5.3.2 Family facilities

Past studies have demonstrated the significance of ongoing practical, emotional and social family support whilst staying in hospital, especially during prolonged periods of treatment (Ritchie, 2001; Woodgate, 1999; Enskar *et al.,* 1997). Hence, good quality family accommodation and facilities are very real requirements for family members, especially those travelling long distances. In light of this, it is encouraging to see in the centre survey that it was standard practice to provide family accommodation, largely free of charge, and in the family survey that children and young people were satisfied and found the provision of a bed for their parents helpful. However, provision and perceptions of quality are not synonymous, and as the centre survey demonstrated, 'family' accommodation usually equates to accommodation for parents. Other family members, such as siblings and grandparents were generally not well catered for; in fact, there was no accommodation for them at around one third of centres. Furthermore, the type of accommodation offered similarly varied. Although it may be common practice to offer more than one type, usually a bed on the ward or self-contained accommodation, degrees of privacy and comfort vary. In light of this variability, it comes as no surprise that family accommodation was an area of dissatisfaction amongst parents in the qualitative group and individual interviews conducted (see Chapter 3). In contrast, amongst parents in the family survey, family accommodation did not emerge as a key area of unmet need, however, high levels of satisfaction were also absent.

The importance of visitors and visiting hours whilst staying in hospital should also not be underestimated and this was clearly demonstrated within the family survey.

Amongst children and young people, visiting hours for family and friends emerged as key areas of satisfaction. Qualitative discussions with children and young people similarly illustrated the importance of visitors and the provision of flexible visiting hours was valued, especially for family and friends travelling long distances or working shift hours.

5.3.3 Transport and hospital catering

Although the survey revealed that it was common practice for most centres to provide some form of transport for families, usually an ambulance, it is important to recognise that despite the popular stereotype of charities providing transport, only just over one fifth of centres reported using charities or voluntary drivers. It is also interesting to note that provision of transport services did not emerge as a key area of satisfaction or unmet need amongst parents in the family survey. With regard to private transport, the clearest result to emerge from both the centre and family survey was the poor provision of parking facilities and the many problems that this raised for families. For example, issues of stress, time wasted finding alternative parking away from the hospital and additional expenditure were all noted in the qualitative discussions with parents. Problematic parking was clearly regarded as an additional and unwelcome burden when visiting hospital.

Although not discussed in the centre survey, within the family survey, hospital food emerged as a key area of unmet need for both parents and children/young people. Parents were particularly dissatisfied with the food on offer to inpatients on treatment. This mirrored qualitative discussions, especially amongst children and young people, where a more flexible approach to food was wanted, such as more snack machines, flexible meal times and a child friendly menu. Many people frequently resign themselves to poor institutional food, however, for children with cancer facing issues of poor appetite and weight loss, the consequences of poor hospital food are very real and stressful, especially when staying in hospital for long periods of time, as alternatives to hospital food are often sought, at families’ own expense.

5.4 Social and emotional support

5.4.1 Assessments and preparation

The family survey demonstrated that support provided by medical staff was a key area of satisfaction for both parents and children/young people. Families particularly valued being involved and feeling respected by staff. For parents, opportunities to be involved in decision making practices were welcomed, especially those surrounding treatment decisions and the development of care plans for their child. For children and young people, how staff treat and approach them were also important. Staff taking time out of busy schedules to talk, listen to their wishes and then follow these through was highlighted as areas of satisfaction. Indeed, this mirrors past literature

(Woodgate, 2000; Van Dongen-Melman, 2000) and our qualitative discussions with young people, where feeling ‘respected’ was a key theme.

At first glance, it appeared that more formalised support, such as psychosocial assessments of new patients were common practice amongst centres. However, on closer exploration of centre survey data, it was apparent that there were very few standard procedures, as many centres noted the informal nature of their assessment process. Assessments varied in the approach taken, the frequency with which they were conducted and the recording procedures adopted. Indeed, in light of current policy directives to standardise children’s services and their procedures (DoH, 2003) it is important to note that only two centres use a recognised assessment and recording framework (Framework for Assessment of Children in Need). Staff experiences, and one can surmise family experiences, are thus varied across the UK. In addition, the survey also revealed that social workers played a key role in the majority of assessments, whereas routine psychological input was infrequent. It thus comes as no surprise that routine psychological participation in meetings discussing patients and their needs was absent, once again, reiterating the general dearth of psychological support and post holders within centres.

Assessments and formal psychological counselling is not the only or always the best way to provide emotional support for families. This was clearly demonstrated in the parents’ survey, where a key unmet need was the provision of both formal and informal emotional support but provided in a low-key manner. Parents would welcome more key worker support, that is an identifiable person, probably a professional, to liaise and co-ordinate services, and more informally, the idea of a ‘befriender’ or ‘cancer buddy’, perhaps a parent who has experienced childhood cancer and has received training to provide telephone or face to face support. Within the literature, the idea of key workers and the importance of having an identifiable person to talk to has been discussed for many years (for example, Greco *et al*., 2004; Sloper *et al*., 1999; Mukherjee *et al*., 1999), it is thus disappointing to see that parents, both in the survey and within the qualitative discussions, still felt that this was an area of unmet need.

Children and young people similarly noted the importance of informal social and emotional support throughout the illness trajectory, particularly friends, both school peers and children in hospital with cancer. Indeed, hospital staff facilitating opportunities for patients to talk to other children with cancer was highlighted as an area where more help and support would be welcomed.

As noted earlier, previous studies (Van-Dongen-Melman, 2000; Jankovic *et al*., 1999; Saunders *et al*., 1995; Huddlestone, 1992) have clearly indicated the importance of preparing and supporting patients and their families over the illness trajectory, especially prior to and during invasive treatments. It is thus positive to note in the family survey that children and young people were satisfied with the preparation for treatment they had received and had found this useful. Results demonstrate that many children and young people valued and were satisfied with being kept informed about their treatment and potential side effects, and receiving advice to make treatment more bearable. This reinforces centre survey findings, where it was reported that play specialists routinely employ distraction techniques and play activities to prepare children for specific treatments. Play specialists are valued but they are also a limited resource, as some centres indicated. However, there were areas where improvements could be made, for example, in the children's survey, children on treatment and young people off treatment indicated that centres could make better use of toys and books in their preparation of patients for treatment. It must also be recognised that play specialists are age related and their work may be inappropriate for teenagers. As previously noted, there is also a need for more teenage activity co-ordinators.

5.4.2 Support groups

Centre survey data indicated that support groups were provided at most centres. However, support was focused upon a specific range of groups, largely parents, bereaved families, teenagers and siblings. With regard to the latter, it is interesting to note that more centres provided support groups for siblings than for children with cancer. Despite this, the parents' survey, especially parents of older children (12-19 years), identified hospital based sibling support group provision as an area of high unmet need. Other family members were also poorly served, indeed, the centre survey revealed that support groups for grandparents were rarely provided.

However, support group provision and perceived need is a complex area, as demonstrated by the family survey. Only a small proportion of children and young people had attended a support group (17 per cent), and groups were utilised and viewed as more relevant by those on rather than off treatment. In many ways this is unsurprising, however, it must also be noted that amongst those who had not attended a group, this was not perceived as an unmet need. Similarly, although many parents welcomed the support of other parents, a telephone network or one to one contact were slightly more popular than group support. The value of alternatives to traditional formal group support is thus apparent. If group support is available, centres need to think carefully about how support is best delivered. The centre survey demonstrated that how groups are organised varied. Some groups meet regularly, others on an ad hoc basis and some groups were organised by hospital staff, whereas others were co-ordinated by voluntary organisations. Perhaps in the future, centres could consider developing more activity based meetings, as this was clearly the preferred option amongst those who did value support groups in the children's survey. Data from parents also suggested developing a telephone network of parents as a possible area for future development, and around a third of parents would be prepared to provide support for others. However, selection of parents and their training needs would need careful consideration.

5.4.3 Leisure and alternative support

The importance of leisure based activities for children and their families was recognised by centres, with provision largely focused upon specific events and activities, such as Christmas parties and summer outings. It is also encouraging to see that support was frequently family based and included siblings and parents. However, in terms of the provision of toys and activities (for in and outpatients), the family survey demonstrated that age appropriate toys and activities were viewed as a key area of unmet need by both parents and children/young people. In particular, there was an expressed need for more appropriate activities for teenagers. Centres were viewed as too child orientated, a view similarly expressed within the qualitative interviews with young people and parents.

Within the literature (Balen, 2000; Balen *et al*., 1998; Stirton *et al*., 1997) the provision of organised holidays for children with cancer and their families is frequently viewed as a positive and worthwhile experience, especially among older children and young people. In light of this, and in contrast to qualitative discussions with parents and young people, it is somewhat surprising that the provision of holidays, both family based and for the child with cancer, did not emerge as an area of key satisfaction or dissatisfaction.

Alternative therapies have recently gained greater credence with a recognition that they can complement medical treatment. Although by no means standard practice, the centre survey demonstrated that around half of centres provided some form of complementary therapy for patients and their families, usually aromatherapy and reflexology. Therapies such as homeopathy, music and art were more rare. Recognising the financial and staffing costs of such services, one must consider if provision is the best use of limited resources, as they did not emerge as key areas of satisfaction or dissatisfaction amongst parents and children/young people in the family survey. Only one third of parents identified alternative therapies as an unmet need and it must be remembered that the study’s sample of parents was slightly over representative of social class one compared to the general population, a group who may have more experience of these therapies in their everyday lives.

5.4.4 Family support

As noted previously, centre services and support tended to focus upon the child/young person with cancer and their parents, other family members were frequently less well served. Although not a major focus of the study, this support imbalance was reiterated by the parental survey. Parents of older children (12-19 years) in particular wanted more support for siblings, particularly someone to talk to siblings at home, in hospital or at school about their brother or sister’s illness. Parents with children of all ages also noted the need for someone to talk to grandparents.

Cultural diversity
As one would expect, provision to meet the cultural needs of families varied across centres. Cultural diversity and recognising the different needs of families emphasises the importance of centres being responsive to their populations (McGrath, 2001; Diefer-Hicks and Lavender, 2001; Woodgate, 1999). Indeed, past studies have highlighted the importance of providing information, both written and verbal in the first language of families (Mitchell and Sloper, 2003; Chamba *et al*., 1999). The survey data presented a picture of varied practice. Although the majority of centres purport to take the cultural needs of different families into account, how and the degree to which they did this diverges. There was no standard practice. Interpreting and translating services were provided at just over half of the centres, these were largely general services. A more personal approach, such as providing first language support workers, was infrequent. Indeed, it is rather disappointing that three centres felt the psychosocial support they provided was not responsive to the culturally diverse population they served. Although a predominately white sample, poor and inconsistent provision was indicated amongst those parents requiring written information in different languages and the services of language support workers, this was clearly an area of unmet need.

5.5 Care issues

Within past literature (Ritchie, 2001; Sloper, 2000; Woodgate, 2000) the important caring role that parents frequently perform whilst their child receives treatment in hospital and the emotional and practical stresses incurred by parents has been much discussed. In light of this, it is positive to see that many parents were satisfied with and welcomed the opportunity to care for their child and act as their care co-ordinator. Indeed, children and young people similarly highlighted that having Mum and Dad help care for them in hospital was very important. Parents once again prioritised being recognised and respected by hospital staff as a responsible and knowledgeable person. However, hospital staff can hold presumptions concerning the degree of support different types of parents require. For example, parents of older children, especially teenagers would have welcomed more breaks from caring for their son or daughter. It is easy to presume that older children do not require as much care and attention as younger children and thus focus support upon the latter. Centre staff need to be aware of the dangers of such presumptions and seek to be responsive to the needs of all parents, irrespective of their child’s age.

5.6 Information and advice

Providing information to children and young people with cancer and leukaemia and their families is an extremely important but, as the literature has demonstrated, complex issue. Families want information presented to them in an accessible and informative manner but it is also apparent that families require different types and degrees of information at different periods of the illness trajectory (Jankcovic *et al*., 1997; Sloper, 1996; Eden *et al*., 1994; Bearison, 1991). It is thus heartening to see that many parents and children/young people were satisfied with the medical information received about their illness. Trying to meet every patient's and their family's needs is a challenge for any centre. However, as past research has indicated, flexibility is paramount, providing a range of information that families and patients can dip in and out of. One way for centres to improve the provision of information is more hospital-based libraries of cancer related books, leaflets and magazines. Such libraries provide an opportunity for families to access information as and when needed, and this provision was highlighted by parents as an unmet need.

Centre survey data indicated that it was common practice for centres to provide more than one type of information. Written information was available as standard practice and play related information for children was provided at most centres. Past literature also highlights the value of audiovisual information, however, it is interesting to note that although video information was provided at some centres (just under half for children), audio information was not available at any centre for children and only at five centres for parents. Poor provision of audio-visual information was also identified in the family survey. Both parents and children/young people would have welcomed more video information about cancer and its treatment, parents in particular wanted more video information for all members of the family. In addition, parents highlighted a need for written summary information about their child's illness and treatment. They felt that this could help them to inform other people, including other professionals and other family members.

As indicated earlier, just under half of treatment centres had online information resources available to families. Hence, it is unsurprising that internet access and facilities emerged as a key area of unmet need in the family survey. However, parents and children wanted more than just access, they wanted specific help to find relevant and quality information. As focus group discussions similarly highlighted, parents recognise the wealth of information 'out there' on the world wide web but have concerns regarding volume and quality control. This need for more internet help was similarly reiterated in the children's questionnaire. This is clearly an area for centres to continue developing, however, it is recognised that there are resource implications both in terms of staff training and hardware.

The provision of family based information was reported as common practice amongst centres. However, separate information specifically targeted for young people was less frequently available. Indeed, parents in the family survey highlighted that they would welcome more age appropriate and specific information for children and young people, especially teenagers and their siblings. Similarly, although most centres indicated that they provided families with a hospital or ward welcome pack, family survey parents still felt that age appropriate welcome packs were an area of unmet need. The provision of separate, age appropriate information for children and teenagers clearly has resource implications both in terms of time and money. However, past studies (Mitchell and Sloper, 2003, Beresford and Sloper, 2000; Diefer-Hicks and Lavender, 2001; Thorne, 2001; Bearison, 1991) have demonstrated that children, including disabled and chronically ill children and young people, have very clear ideas how they would like information to be provided, i.e. in an age appropriate, accessible manner. Similarly, although around half of the centres noted that they involved families in the production of information, only six had worked with children. This is not to say that some centres do not prioritise and strive to provide accessible information for children and young people, however, it was not standard practice across centres, a factor accentuated by the absence of formally recorded policies for information provision.

Recognition that families often face additional expenditure and changing financial circumstances across the illness trajectory, especially in terms of juggling paid employment with caring responsibilities has gained increasing credence (Corden *et al*., 2002; Yantzi *et al*., 2001; Sloper, 2001; Stein and Woolley, 1990; Halliday, 1990). Thus, it is heartening to see the majority of centres reported provision of a designated person (usually a social worker) and help in completing application forms (such as Disability Living Allowance) as standard procedure. Indeed, the importance of Sargent social workers fulfilling this role was highlighted. However, the voluntary sector survey identified financial support for teenagers as a specific area of potential service gaps. In light of this, it is somewhat surprising that financial information did not emerge as a key area of satisfaction (or even dissatisfaction) for parents or young people (16 years plus) in the family survey.

5.7 Transition issues

5.7.1 Hospital to home

Support before, during and after the transition from hospital to home is recognised as pivotal for both patients and their families. It is thus encouraging to note that centres reported provision of a hospital to home outreach service and procedures for the transition home as common practice. Nursing staff were the most frequent providers of outreach support and were also usually the designated person responsible for handover procedures.

The centre survey data demonstrated that outreach support was usually provided via home visits and telephone advice, with continuing social work support available to families if required. The importance of this support, especially a clear and accessible phone network was reinforced by the family survey, as parents indicated that they were particularly satisfied with the telephone advice they received or knew they could receive if concerned about their child. However, support needs to be ongoing, and parents with children/young people off treatment wanted a more pro-active hospital to home service, with staff actively contacting them by phone.

This perceived lack of pro-active procedures is probably exacerbated by the fact that many centres apply informal rather than formal hospital to home procedures. Having a ‘chat’ or ‘discussions’ with patients or family members can take many different forms and is thus open to interpretation and varying degrees of support. Parents with children off treatment wanted hospital to home handovers to be more co-ordinated. Indeed, the idea of an end of treatment meeting with a group of parents (some of whom have previously negotiated the hospital to home transition speaking to parents currently facing this transition) and hospital staff was welcomed by parents of children off treatment. It is also important to prepare children and young people for the transition home, the children’s survey revealed that children wanted hospital staff to spend more time talking to them about being at home. This may indicate that centres tended to focus upon young people and were less likely to recognise the needs of younger children.

Returning home can also be a time of family relationship change (Yantzi *et al*., 2001; Van Dongen-Melman, 2000; Sloper, 2000; Halliday, 1990). Regaining or beginning to establish independence was highlighted as an important issue in the study’s qualitative interviews. Children and young people in the family survey similarly reiterated this, as they valued hospital staff providing independence opportunities. Simple but effective ways to help children and young people take more control of their life were demonstrations of how to look after equipment or take one’s medicine. However, support to deal with broader relationship changes (parental and sibling) was not identified as an area of unmet need by children and young people. In contrast, the need for support to cope with family changes was much discussed in the qualitative interviews with parents and the need for provision of more couples counselling has already been noted. In addition, the voluntary sector survey also identified support to prevent relationship breakdown as an area where service gaps exist.

5.7.2 Community based practitioners

Well co-ordinated and continuous support from community based professionals is frequently noted as invaluable but, as past literature has suggested, this is not always the experience of families with chronically ill or disabled children (Hunt *et al*., 2003; Mitchell and Sloper, 2001). Lack of communication and joint working amongst hospital and community based professionals is highlighted as a common problem. Many centres reported that outreach staff (largely nurses) generally met with community-based professionals and arranged joint visits, but this was usually with a limited range of health professionals (GPs and health visitors); liaison with community based social workers and therapists was less frequent. The family survey demonstrated support from community based practitioners was not an area of satisfaction for parents. Indeed, parents of children (0-11 years) identified support from GPs as an area of unmet need. The types of support needed included GPs being available for advice when the child was ill at home, counselling support, and advice on normal developments of childhood.

5.7.3 Returning to school

The importance of school and the normality that it can represent within patients and their families' lives is generally recognised. However, as documented earlier, returning to school requires careful planning and preparation between schools, treatment centres and families. Indeed, past research has documented the benefits of clear, well co-ordinated procedures (Vance and Eiser, 2002; Faulkner *et al*., 1995; Larcombe, 1995). It is thus positive to note that it was common practice in the vast majority of centres to have a designated person responsible for assisting the transition of children and young people returning to school. This was usually a nurse or teacher, with liaison frequently taking place in the school. However, the clarity and effectiveness of these named people from the family's point of view must be questioned in light of family survey data and a recognition by key agencies in the voluntary sector survey that returning to school procedures are often *ad hoc*. Parents welcomed the idea of an education coordinator to oversee return but few had experienced this. Indeed, the current situation is not aided by the lack of uniformity amongst centre policies and practices, with less than half of centres having their returning to school policies formally recorded. Once again, informal procedures can be interpreted in many ways, so, although involving families may be recognised, ensuring certain practices and standards is difficult.

Amongst family survey respondents, children and young people appeared to have a more positive perception and experience of returning to school than parents. Indeed, the latter did not highlight any key areas of satisfaction, whereas children and young people were generally satisfied with both the practical and educational support they received before and on return to school. However, it must be noted that children and young people were asked to consider immediate practical and educational issues, such as dealing with changed appearance and catching up with their studies, whereas parents focused upon broader and more abstract organisational issues.

Clear information is also pivotal in transition preparations. Centre survey data highlighted that staff valued the 'Welcome Back' booklet published by Cancer Research UK. However, the degree of returning to school information families received appears to be variable. This was clearly demonstrated in the family survey, as parents of school age children wanted more written and video information for their child and their siblings and school peers about cancer and its treatment.

5.7.4 Transition to adult services

The family survey did not specifically address the transition from child to adult services. However, centre survey data clearly indicated that there was a lack of consensus surrounding care transitions and uniformity of practice amongst centres for both patients on treatment and survivors. Some centres did not have a hand-over, whereas others did, but the age at which this occurred varied considerably. This mirrors past concerns and issues raised in the literature generally regarding the transition of young people from paediatric to adult services (Morris, 1999; Swain and Thirlaway, 1994), and more specifically, from child to adult cancer services. Thus, it comes as no surprise that none of the centres had formally agreed policies or practices in writing.

5.7.5 Long-term survivorship

Ongoing psychosocial support for long-term survivors is similarly an area which requires greater clarity and prioritisation, especially in the context of the increasingly positive survival rate that many childhood cancers now face. There is increasing awareness of the problems that long-term survivors can face (Diefer-Hicks and Lavender, 2001; Roberts *et al*., 1998; Eiser, 1998; Puukko *et al*., 1997; Lozowski, 1993). Centre survey data demonstrated that there was little consistency amongst centres; only three centres had policies formally recorded in writing. Provision was also extremely variable ranging from support provided as and when required by each individual to attendance at annual survivor clinics. Despite this lack of uniformity, there was a great deal of satisfaction with hospital checkups and the support received at these clinics amongst the small number of survivors completing the children’s questionnaire. Provision of ongoing medical support was clearly valued.

Discussion of fertility issues, although a complex area, is increasingly recognised as an important part of psychosocial support (Crawshaw *et al*., 2003; National Institute for Clinical Excellence, 2003). It is thus disappointing to see that parents, especially of young (0-5 years) and older (12-19 years) children wanted more support around fertility issues for themselves and their child. It is also important to note that nearly a fifth of children and young people were unsure if fertility issues had been discussed with them. Fertility is a sensitive and often difficult subject to raise but there is an obvious need for hospital staff to consider how they are approaching fertility, especially issues of clarity. Nevertheless, the sensitivity with which fertility matters were handled by staff was a source of satisfaction for parents.

5.8 Palliative care

As explained previously, this study did not include a sample of bereaved families or those experiencing palliative care, as issues of sensitivity and the potential diversity of experiences could not be adequately addressed within a generic psychosocial family survey. However, a number of issues were explored within the centre survey and it is positive to see reported as common practice that centres offered families a choice(s) of where they would like care to take place: hospital, home and/or hospice. Similarly, it is also encouraging to hear that a 24 hour on-call service was routinely provided at most centres, frequently by an outreach team with expertise in palliative care. On the other hand, specific details about access to children’s hospices and how centres work with them varied, some centres were vague and the information provided was partial. In addition, it is also interesting to note that four centres highlighted problems of accessibility for patients and their families, focusing upon issues of distance and availability of children's hospice provision. Although this is a relatively small proportion of the centres, these issues and concerns mirror problems that have been raised within previous and more in-depth studies of children’s hospices (Robinson and Jackson, 1999).

Bereaved families similarly face varied levels and types of support across the UK with only around a third of centres providing support in the home, largely from social workers or nursing staff. However, it is somewhat heartening to see that over half of the centres referred families to external bereavement agencies. Although bereaved families will have different support needs and preferences at different times, providing families with such information and support options is extremely important.

5.9 Psychosocial support for centre staff

At first glance, centre survey results appeared to suggest that regular psychosocial support for staff is common practice. However, on closer analysis it was apparent that staff support varied enormously across centres due to informal provisions and practices. Staff support was provided in different formats, from group or individual meetings to a mentoring scheme, and with different levels of frequency. Similarly, some centres had a designated person providing support, whereas others relied upon colleagues. In light of such varied provision, it is unsurprising that there was no clear pattern of take up for staff support. This is not to say that staff support is unimportant. Indeed, centre staff themselves highlighted this as an area in need of development and more formalised systems.

5.10 Concluding comments

The positive response received to the centre survey demonstrates that the importance and value of providing psychosocial support services to children and young people with cancer and their families is generally accepted and respected. Indeed, the family survey showed that parents and children/young people were satisfied with many areas of psychosocial service provision. Although this report has focused upon key areas of satisfaction (70 per cent plus), there were many other areas falling just below this and in general there was more satisfaction than dissatisfaction. A number of shared areas of satisfaction emerged encompassing information and interpersonal support. Both children/young people and parents were satisfied with and valued the medical information they had received and the personal support provided by hospital, social and educational staff. How support had been received was crucial, children/young people and parents alike valued being respected as a knowledgeable person and involved or consulted in care and treatment planning and decision-making.

However, these positive results should not obscure the fact that there were still numerous areas of unmet need that require further development and would significantly improve children and young people with cancer and their families' lives. The key message from the centre survey is variation across centres, in terms of the range of facilities available to families and the absence of standard practice and procedures that centres implement. This is frequently the result of an informal/formal divide, where practices may be acknowledged and respected but how, when and the degree to which they are implemented can vary. This was particularly pronounced with regard to issues surrounding transition (hospital to home, returning to school, child to adult services and long term survivorship) and reinforced by the parents' questionnaire, which demonstrated a continuing need for improved service and information co-ordination. Centre data demonstrated that patterns of support were frequently ad-hoc and unrelated to discernable factors, such as the age or range of patients served or centres' areas of specialism.

In light of this, there is a very real need for agreed standards. The Children's National Service Framework Hospital Standard (Department of Health, 2003) sets out standards that all hospital services must meet. These specify that services should be child-centred and provide care that is integrated and coordinated around the child and family's needs, including support and information; children and parents should be active partners and participate in designing services; care should be high quality and evidence-based, delivered by staff with the right skills; and the environment should be 'safe and well suited to the age and stage of development of the child'. The full National Service Framework, which is due to be published later this autumn (September/October 2004), will set out further standards for children with long-term illnesses. The importance of such guidelines is also recognised by the National Institute of Clinical Excellence (NICE). NICE are currently developing 'Service guidance for improving outcomes in child and adolescent cancer' (first consultation this Autumn, publication scheduled for June 2005), although not specifically focused upon psychosocial services, the importance of psychosocial support is recognised, especially at key times, such as the transition from treatment and long term survivorship.

The survey data suggest that much good practice in relation to hospital standards already exists in paediatric oncology centres. However, the variability between centres and the lack of formal agreed policies and procedures for provision of psychosocial support indicate that not all children and families will receive a comprehensive package of support to meet their needs. It is clear that in order to ensure that all centres meet the standards set out in the NSF and guidelines more specific to childhood cancer (for example, ICCPO, 2000) more formal policies and procedures need to be established and implemented, as informality can accentuate variability and diversity amongst centres.

The results of the two surveys (centre and family) frequently concur; six broad areas come to the fore in terms of poor provision and unmet need:

- There is a shortage of staff able to provide psychological support and a dearth of counselling options and opportunities available to families, especially parents.
- There is still a great deal of variability in the teenage facilities centres provide and different families experience. The number of centres with separate teenage units and facilities is continually growing; this is often a result of the work of the Teenage Cancer Trust. However, even within separate units, there are still areas of unmet need.
- The importance of age appropriate activities may be recognised but there is still a need for hospitals to provide more age appropriate leisure activities and facilities, especially for teenagers.
- The provision of information varies across centres and although different families have different needs and requirements at different phases of their illness, information in different formats, particularly audio visual and specifically targeted and appropriate for different age ranges and family members, continues to be an unmet need.
- Online information resources and support varies across centres, both parents and children/young people require more help accessing relevant information.
- Centre support does not always extend to other family members, such as siblings or grandparents. Extending support to routinely include siblings and considering the needs of grandparents is an area requiring further development. In addition, although parents may be satisfied with the care of their child, parents frequently felt that they themselves required more emotional and practical support.

These are areas that clearly require further development and consideration. However, it is important to appreciate that CLIC does not work in isolation, collaboration and co-ordination with the statutory sector and other voluntary agencies is important, a factor generally recognised within the voluntary sector survey. In addition, not all areas may fall within the remit of CLIC. Some issues, such as the NHS wide shortage of psychologists, are areas for government and policy makers to address. In this particular area, action is already taking place, recent increases in the number of places on clinical psychology training courses are beginning to fill the gaps in psychology provision. Similarly, although CLIC may wish to help improve teenage facilities and the provision of social workers, it is recognised that voluntary organisations, such as the Teenage Cancer Trust and Sargent Cancer Care specifically focus upon these areas. However, as noted earlier, CLIC funds a small number of play specialists, this is an area that could be extended and developed. In addition, the study's results also suggest that CLIC could consider the following broad areas:

- Improving and extending accessible age appropriate information available in a variety of formats, and addressing the information needs of other family members (siblings and grandparents), school peers and those whose first language is not English.
- Exploring a range of counselling and support options for families, including parents, siblings and grandparents. This is a complex area with issues as diverse as relationships between couples, and just having 'someone to talk to' raised by the study. One underlying theme is the importance of utilising parents' experiences, hence, the popularity of a 'cancer buddy scheme' and a telephone network.
- Further exploring the scarcity of psychologists in many centres. With increases in people coming off training courses, there may be an opportunity for CLIC to fund or part-fund posts in some centres.
- Providing more age appropriate leisure options, including the provision of toys, the range of leisure activities available to children and young people whilst staying in hospital or visiting as day/out patients, and the provision of activity coordinators and/or youth workers for teenagers.
- Facilitating contact between children and young people with cancer, preferably through activity-based groups, rather than 'support groups'.
- Funding transition coordinators or key workers, identifiable people who ensure that information is communicated and passed on to all parties, liaise with relevant services and keep families informed. This is clearly a broad and diverse area, as there are numerous transitions across the illness, however, the importance of having someone to 'take control' was continually reiterated.
- Finally, there are some clear gaps in research knowledge on psychosocial support, in particular we know little about the views of grandparents and siblings themselves about the support they need and receive. Information from the family survey is proxy information obtained from parents. As we have seen from the comparison of parents and children's views, there are likely to be differences of opinion and emphasis between the views of parents and siblings' and grandparents' own views. In other areas of the survey, data were only obtained from small numbers of respondents. Minority ethnic groups were poorly represented and specific research focusing on these groups is needed. Similarly, numbers of long-term survivors were small and more targeted research with this group could provide valuable information on support needed.

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